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UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

Case Study of Parents Caring for a Child Having Type-1 Diabetes With Optimal HgA1c

by

Elizabeth Ciaccio

**A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
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July 17, 2012

Dissertation Committee

**Jane M. Georges, PhD, RN, Chairperson
Cynthia D. Connelly, PhD, RN, FAAN
Linda D. Urden, DNSc, RN, CNS, NE-BC, FAAN**

ABSTRACT

Type I diabetes in school age children is a complex condition requiring continuous physical, nutritional, and therapeutic monitoring to prevent lifelong complications and maintain quality of life. In 2011, one in 400 children in the United States were affected by it. The purpose of this research study was to understand how parents achieve optimal HgA1c for their school age children with type-1 diabetes. Currently, there is very little research documenting how parents achieve this goal. Understanding this phenomenon more clearly can be used to inform future research, improve practice and provide information for development of effective health policy.

Management of diabetes in school-age children is a challenge for parents because of the requirement for variable insulin regimes, and is complicated further by the child's ever-changing needs due to growth and development and inability to identify potentially harmful hypoglycemic episodes. Yin's case study methodology was utilized in this study with Parse's human/becoming theoretical framework as an analytic basis. Careful attention throughout the study was paid to demonstrating rigor. Data were triangulated using rival midrange theories, cross case comparison, observations and literature. The three cases used for the cross case comparison represented three distinct ethnic groups. The human/becoming theory most closely supported the outcome of the data analysis offering evidence of rhythmicity, co-transcendence and intentionality. Each case analyzed consistently communicated similar experiences in the various phases of pre-diagnosis, hospitalization and diagnosis, discharge, stabilization and preparing the child for independence.

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DEDICATION PAGE

I began my PhD experience with the loving support and encouragement of my friends and family. Throughout my life, regardless of the obstacles before me, I always was confident that all of my loved ones were behind me to pick me up in times of grief and cheer me in times of success.

My father, who rose out of his family's circumstances as poor Italian immigrants to achieve things his ancestors never dreamed possible, particularly inspired me. I am forever grateful for the sacrifices and support he provided generously. He was truly a role model both spiritually and intellectually.

My mother, who came from a long line of overachievers always made me feel as if I too was capable of achieving anything I set my mind to.

My brother Roderick and sister Mary along with their families were always there along the way to encourage and cheer me on. Patrick "Duffy" Tweedy was always on standby to help me locate that obscure article I just had to have. Each of them has made the world a better place because of their contributions.

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All of my patients past and present I am honored to give you voice and that you have allowed me a glimpse into how strong you all are. My coworkers who have expressed pride in my journey and my accomplishments.

Most of all I am grateful for a God that has created all of these wonderful people that have shaped my life. I humbly raise up this accomplishment as a gift to you.

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Introduction

Diabetes mellitus, referred to as diabetes, is a group of chronic, incurable life long metabolic disorders marked by high blood sugar levels. The World Health Organization has estimated that from the year 2000 to 2030 the incidence of diabetes will increase by 114% ("World Health Organization," 2011).

Diabetics are at risk for a variety of complications ranging from heart disease, kidney disease, amputation, hypertension, blindness, and neuropathy ("American Diabetes Association," 2012). Quality of life is adversely affected as a result of complications suffered by a diabetic individual. One of the stated goals of Healthy People Initiative 2010 was to decrease the morbidity and mortality of diabetes ("Healthy People," 2010).

While incurable, diabetes can be controlled. Evidence-based therapeutic approach to disease management revolves around careful and continuous attention to glycemic levels requiring complex regimes of diet, medications, exercise, stress reduction and overall healthful living practices ("American Diabetes Association," 2012).

Although diabetes can occur at any point during the lifespan and is precipitated by multiple factors, one condition within the broader disease classification, Type-1 , is commonly diagnosed in children and youth ("American Diabetes Association," 2012). Type-1 diabetes is characterized by autoimmune destruction of the pancreatic cells responsible for insulin production ("National Diabetes Information Clearing House (NDIC)," 2011).

One in every 400 children has been diagnosed with type-1 diabetes, which affects about 25.8 million children in the United States. Three quarters of all type-1 diabetics are

diagnosed at less than 18 years of age ("American Diabetes Association," 2012). The ADA recommends that children maintain a HgA1c, which measures glycemic control over the previous three months, at less than 8% ("American Diabetes Association," 2011). The Centers for Disease Control (CDC), National Committee for Quality Assurance (NCQA) , and National Diabetes Information Clearinghouse (NDIC) , collect no specific data on HgA1c on school age children or the American Diabetes Association that reflects how well this population is controlled. As such the percent of children in the United States with type-1 diabetes with an optimal HgA1c is unknown ("American Diabetes Association," 2012; "Centers for Disease Control (CDC)," 2011; "Centers for Disease Control (CDC)," 2012; "National Committee for Quality Assurance," 2011; "National Diabetes Information Clearing House (NDIC)," 2011).

Gaps in the Literature

Although the ADA offers guidelines for the care of children with type-1 diabetes ("American Diabetes Association," 2012), parental involvement in the day-to-day care approaches of the disease is not completely understood. Much can be learned from parents caring for children successfully. This study seeks to elucidate parental involvement and insights on the care of their school age children with type-1 diabetes who have good glycemic control.

A large body of evidence exists in the literature addressing parents caring for children with chronic diseases including diabetic children. These studies ultimately attempt to provide information to improve patient outcomes. Empirical evidence targeted at interventions to manage the disease as guided practice with some success. There is still a large gap in understanding behaviors and beliefs of those tasked with the management

of children with the disease. The literature provides information on the impact of the disease on the family and even more specifically some approaches and interventions that may be useful to a parent of a child with a chronic disease. This same literature also acknowledges the results of studies do not fully explain the variations in glycemic control, and more investigation is necessary to fully understand good glycemic control. Thus, it is important to better understand how parents achieve optimal glycemic control.

Statement of Purpose

This dissertation research is important because it will evaluate the phenomenon of parents caring for children with type-1 diabetes experiencing optimal glycemic control. Parse's human/becoming theory will provide the theoretical framework for this study (Parse, 1992). The ADA guidelines of a HgA1c of 8 or less will be used to define good glycemic control ("American Diabetes Association," 2012). The majority of chronic disease management occurs outside of the provider setting. If the child's disease is stable, as reflected by HgA1c, it is likely the parents have learned effective ways of caring for the child. To address the gaps in the care literature of type-1 diabetes management, a qualitative methodological approach will be used to understand how parents care for the well-controlled child with type-1 diabetes. Specifically, a rigorous case study methodology will be utilized to respond to the research question of how parents successfully care for their school age child with type-1 diabetes providing new knowledge to support future research and health policy.

There are differing ideas about what a case study is (Gillham, 2000; Merriam, 1998; Miles & Huberman, 1994; Stake, 1995; Yin, 2009) . This study will follow the philosophical underpinnings of Yin, with an emphasis on his methods and techniques.

Utilizing Yin's methodology offers an explicative analysis of the phenomenon under study.

This case is purposefully selected for information that is rich and critical to understanding the phenomenon of parents living with type-1 diabetic children who are experiencing good glycemic control. Participants will be limited to those parents with school age children that have type-1 diabetes. Currently the ADA recommends a target HgA1c of less than 8 for this age group.

It is well documented by the Diabetes Control and Complication Trial that good glycemic control early in life can delay the onset and progression of complications (*Diabetes Control and Complications Trial* 1993). Because of the impact diabetes has on individuals, as well as society, it is important to understand meaningful care approaches for parents to manage their child's disease.

Summary

Reviewing the literature demonstrates a gap in knowledge in the general area of chronic disease management and how families living with an individual experiencing chronic disease manage it successfully. Case study methodology utilizing Yin's strategies will provide the philosophical underpinnings of this study. Yin bases his approach on the constructivist claim that truth is relative and dependent on the lens used to look at the data (Yin, 2009). Yin's approach to truth is supported by the hermeneutic movement that posits the researcher cannot be totally separated from the research and brings his/her own world experience to it (Charmaz, 2006).

The researcher is approaching this study as a single middle-aged white female with a chronic disease (Multiple Sclerosis) that is currently controlled. The researcher has

no children. She is a nurse with pediatric and newborn experience, but no experience with childhood chronic disease management. Currently, she is working on the financial side of the health care delivery system. The researcher is an interpretive/explicative researcher and scholar who believes in the value of theoretically informed practice, research and health policy. A large body of qualitative research exists that uses analytical tones of discourse and ignores the interpretation of the data and how ambiguities are treated (Charmaz & Mitchell, 1996). The researcher for this study does not intend to include the interpretation of the data and address ambiguities.

The intention of this study is to explore the phenomenon of school age children with type-1 diabetes as humanly experienced by the parent (Dilthey, Makreel, & Rodi, 1991). The data collected during this study will provide thick description of multiple data sources allowing the interpretation to be triangulated as described by Yin (2009). The results of this study will help to inform health policy and can be explored further through other research methodologies within diabetes and across other chronic disease populations.

The literature review conducted in preparation for this study was done to identify gaps in knowledge. Data analysis will occur concurrently with pattern matching and triangulation to build the analysis (Yin, 2009). This process will include ongoing literature review as the analysis evolves. The more rival propositions are explored the more the confidence in the findings will increase (Yin, 2009).

Chapter II

REVIEW OF THE LITERATURE

Background: Diabetes, the Disease

Diabetes mellitus refers to a group of metabolic conditions categorized by their etiology. All forms of diabetes share commonalities. Some of these commonalities include elevated blood sugar, pathology caused by micro vascular compromise and a chronic disease status ("American Diabetes Association," 2012). Type-1 diabetes will be the focus of this study.

Type-1 diabetes is defined by a lack of insulin production by the pancreas. It can be caused by a combination of genetic factors and environmental factors, creating an autoimmune response that is not fully understood ("National Diabetes Information Clearing House (NDIC)," 2011). According to the National Institute for Health ("Immunopathogenesis of Type 1 Diabetes Mellitus," 1997) only 35% of monozygotic twins are concordant for type-1 diabetes. This statistic supports the idea that there is more than genetics responsible for the disease process. Onset of type-1 diabetes normally occurs in childhood ("American Diabetes Association," 2012).

Complications of type-1 diabetes are triggered at the micro vascular level and can range from hypertension, organ failure and even death ("American Diabetes Association," 2012). Individuals diagnosed with diabetes of any type have a death rate twice those without the condition. The direct and indirect cost is 2.3 times greater than those without diabetes in the United States ("Centers for Disease Control (CDC)," 2011). The cost of human suffering is immeasurable.

The ADA provides guidelines for clinicians to manage the disease based on the state of current literature. The guidelines include the frequency of testing various organ functions as well as target levels for HgA1c. The ADA website also provides information

and resources for patients and families of diabetics. Patient and family information includes major categories such as: Everyday life, Diabetes Care at School, Managing diabetes, Family Communication, Planet D (specifically for children and teens) and Diabetes Camp ("American Diabetes Association," 2012).

Disease management has been studied from many different perspectives. Diabetes is considered a chronic disease, and these studies have provided a basis for research about specific conditions. Studies have also been specifically conducted on type-1 diabetes and its impact on children and their parents. Clinicians have used literature in chronic disease management including diabetes management to support evidence-based practice in the attempt to achieve good diabetic control. Disease management has been studied from many different perspectives.

Current literature on diabetes indicates that in the aggregate the disease is not well controlled. In addition, large-scale studies show that complications arising from poor control are common ("Healthcare Effectiveness Data and Information Set ", 2012; "World Health Organization," 2011) ("American Diabetes Association," 2011). Very little outcome data is available specifically for children. In an Issue Brief the National Commission on Quality Assurance reported that what is known about children pales in comparison to the breadth and quality of data gathered for adults. It also reported that the majority of data currently gathered for children were encounter type data reflecting the number of visits to providers and immunizations (Scholle, Sampsel, Davis, & Schor, 2009).

Complications for diabetics are a reflection of poor diabetic control ("American Diabetes Association," 2011). In order to quantify the health problems experienced by

children with diabetes, the Healthcare Effectiveness Data and Information Set (HEDIS) was reviewed on the NCQA ("National Commission on Quality Assurance," 2008) database. All children were categorized in the age grouping "under eighteen". According to HEDIS data, approximately 41.5% of those under the age of 18 are well controlled exhibiting no complications from the disease ("National Commission on Quality Assurance," 2008). In spite of the volume of literature published on type-1 diabetes it appears that useful care approaches to achieve good glycemic control are not well understood.

Literature Review

In the sections to follow, the literature on disease management will be reviewed. The aims of this review are two fold. First the gaps in our understanding of parental involvement in the care of their child with type-1 diabetes will be evaluated. The second aim of the literature review is to situate this proposed research in the broader field of knowledge on the topic. (Charmaz, 2006) suggests that a literature review is useful for identifying the potential contribution of the research to the broader field of study. The literature will continue to be consulted to once data collection and data analysis commence (Wuest, 2010; Yin, 2009).

This review will include both quantitative and qualitative studies of chronic and diabetes illness management in children. Since diabetes is categorized as a chronic disease this literature review will look first to the research conducted on chronic disease during childhood. The focus of the chronic disease literature review will be on care approaches that may be useful in the diabetic population and would provide useful information for further research in this specific group of children. This will be done prior

to moving into the literature specific to diabetes.

Studies of chronic disease in children. A significant amount of research exists on the response to chronic illness by members of the family. Some studies, such as the one conducted by Knafl and Deatrick (1987) used Voysey's framework to differentiate parental response to chronic disease based on the parent's perception of the disease. In Voysey's framework, families who care for children with chronic illness are divided between two main categories. The first category includes family members who view the child with a chronic disease as inherently negative, ultimately impacting family life adversely. The second category is characterized by a more positive view of the child with the chronic disease having less of a negative impact on family life (Voysey, 1975). Other studies on the impact of chronic disease management use the Objective Passive Outcome Approach to focus on parenting approaches (Cairns, Clark, Smith, & Lansky, 1979). This approach to understanding parent behavior in managing chronic disease in a child ignores the subjective dimension of the process and relies on the parent's interpretation of objective outcomes (Knafl & Deatrick, 1987).

The involvement of parents in the management of their child with a chronic disease has been explored by Wysocki and Gavin (2006). Their study used a cross-sectional survey methodology to measure treatment adherence, quality of life, health status, and healthcare utilization for youths having one of six different chronic diseases concluding parental involvement was associated with better measures (Wysocki & Gavin, 2006). Their study did not address ongoing care of the child but only measured a point in time. It also did not address which strategies of involvement improved measures.

Professionals who provide support and education to families with a child who suffers from asthma and allergies were studied using a mixed methods approach (Stewart et al., 2010). The study utilized a 26-item survey tool and qualitative interviews, which focused on the learning needs of these professionals. The study participants felt that there were barriers such as time and money that blocked their needed education. The researchers concluded that health professionals were unable to provide support due to limited financial resources, time and options for asthma related activities that they felt would be useful to the families (Stewart et al., 2010). This study overlooked the needs of the parents and the outcomes these parents were achieving.

Diabetes literature. The American Association of Clinical Endocrinologists states: “managing diabetes mellitus requires a team approach to patient care. However, because diabetes is primarily a self-managed disease, education in self management skills is essential in implementing interventions” (Rodbard et al., 2007). Since children are not mature enough to self manage their diabetes alone, their parents are included in this study as part of the self-management process. Because this is primarily a self-managed disease the literature review for diabetes will focus first on research that seeks to identify interventions intended to improve self-management. Attitudes and beliefs as measured by survey methods will then be reviewed since these types of studies can be used to inform research that investigates interventions. Finally the state of qualitative research will be reviewed looking at the phenomenon of diabetes self-management.

Interventional studies in diabetes mellitus. Interventional studies aimed at improving outcomes of diabetes management show some promise but do not fully explain the variations in outcomes experienced by children. These studies will be broken

out into three main categories. The first category is interventions targeted at assisting patients with glucose monitoring. The second category is interventions targeted at education related to components of diabetes management such as diet and physical activity. The third category is interventions targeted at improving psychosocial support.

Some improvement in glycemic control was identified in studies utilizing a continuous glucose monitoring system (CGMS). A CGMS is a Food and Drug Administration (FDA) approved device that monitors blood sugar around the clock. A comparative study of glucose monitoring techniques of children between the ages of 8 and 18 with type-1 diabetes found glycemic control improved with both CGMS by parents who coupled the CGMS with monitoring intermittently using a glucose strip (Deiss, Hartmann, Hoeffe, & Kordonouri, 2004). Additional studies on type-1 diabetes focused on various age ranges evidenced similar results (Jeha et al., 2004; Ludvigsson & Hanas, 2003; Tanenberg et al., 2004; Weintrob et al., 2004) .

A meta-analysis conducted with 12,756 citations focused on the effectiveness of diabetes education on children and their families. These authors concluded the methodological quality was low in many of the studies and there was little evidence supporting the effectiveness of diabetes education on glycemic control. Educational strategies were broken down into the categories of: cognitive behavioral therapy, family therapy, skills training, and general diabetes education (Couch et al., 2008). The results of this meta-analysis provide strong evidence that patient and parental needs are not well understood.

An interventional study targeted at coping skills combined with education was compared to general diabetic education for school age type-1 diabetic children. In this

study, both groups showed some improvement in diabetes self-efficacy, coping, less need for parental involvement, and glycemic control. The changes in HgA1c were minimal (.29 to .52) but significant at $p < .001$. HgA1c was not initially poorly controlled in this population when comparing to the ADA recommended standards. This study had a mean HgA1c between the two groups of 6.98 and 7.11 with a standard deviation of 1.33 to 1.21 respectively. The framework used for this study was the stress-adaptation model which views adaptation to chronic illness as a process of adjustment by the individual. This study used a randomized trial with 82 participants and concluded any type of group intervention would improve outcomes and the specific intervention itself was not the deciding factor of the evidence of improvement (Grey et al., 2009). The impact of this intervention on poorly controlled diabetic children might be more meaningful than the impact on a population already well controlled.

Stress management training has focused on the stress associated with the various aspects of managing type-1 diabetes. (Attari, Sartippour, Amini, & Haghighi, 2006) obtained significant results ($p < 0.001$) as reflected by changes in the patient's HgA1c in a study conducted on type-1 diabetics between the ages of 16 and 30. In this study, stress management training focused on multiple area of stress management including: personality, environment, physiological, psychosocial, diet, and lifestyle. This study was designed using a medical model since the researchers represented medicine at academic institutions. No theoretical framework for this study was stated. The type of stress addressed with the study group was not correlated with the types of effects on the participant (Attari et al., 2006). Additional studies are required to attribute the drop in HgA1c to specific areas of diabetes management.

Interventional studies targeting parents and their school age type-1 diabetic child are very limited in the literature. None of the studies reviewed provided evidence of care approaches that would significantly impact the outcome of a diabetic child's care. There is not a good understanding of what are meaningful interventions for children and their caregivers.

Surveys. Surveys have evaluated beliefs and attitudes impacting outcomes but fail to explore in depth those beliefs, experiences, and attitudes that are important to the patient and parents. Surveys include a limited number of options for responses and do not provide the participant a vehicle for providing additional insights. The usefulness of the results of each survey is dependent on the reliability and validity of the tools used to gather the data. Surveys have been used to evaluate and predict educational needs, social support, and quality of life of diabetic children and their families with limited results.

The choice of theoretical frameworks for research targeted at children or individuals with various forms of diabetes has grown from other areas including those outside nursing and medicine. The self-regulation model, developed by Leventhal, Nerenz and Steele (1984) grew out of cognitive social psychology and was used by Skinner and Hampson (Skinner, John, & Hampson, 2000) as a framework for prediction of self-care by adolescents with diabetes. This study by Skinner and Hampson (2000) used a longitudinal survey method and concluded personal models of self-care interact with social relationships in predicting the outcomes of the participants' well being. This study used a small sample size of 52 but maintained rigor through documentation of the methodology, as well as the reliability and validity of the measurement tool. Applying a

cognitive social psychology framework to this study may have led the researchers to overlook issues which could have affected glycemic control (Skinner et al., 2000).

Some quantitative studies using a psychosocial or educational framework to determine the impact on diabetes outcomes such as glycemic control have a small to moderate impact clearly demonstrating the need to have a more in depth understanding of the behaviors and beliefs that impact outcomes (Hampson et al., 2001; Murphy, Rayman, & Skinner, 2006). A study by Wilson et al. (1986) used social support as a component of predicting diabetes outcomes and found social support and psychosocial measures were the best predictors of glycemic control. This study used a sample of 184 adults with non-insulin dependent diabetics and a wide variety of measures were collected to determine predictors of glycemic control. Investigators concluded that while there was significance to using social support and psychosocial measures to predict glycemic control there were a variety of regimes within the patient population that confounding the results indicating the need for further study (Wilson et al., 1986). An exhaustive search of CINAHL did not reveal any additional studies expanding on the focus of this study beyond the areas of social support and psychosocial factors.

Health related quality of life was measured in a study by Wagner, Muller-Godeffroy, von Sengbusch, Hager and Thyen (2005). The authors of this study evaluated Health Related Quality of Life (HRQOL) as a psychosocial measure of outcomes of type 1 diabetes management in both school age (8-12) and adolescents (13-16). They had a sample size of 68. HgA1C ranged in this study from 6.3 to 9.3 and included a group of non-diabetics to compare and contrast results. This study concluded school age children with type-1 diabetes perceive similar levels of HRQOL as their healthy peers and

therefore had similar psychosocial outcomes. Since the study participants were recruited from a tertiary care clinic, that included diabetes as a specialty, the positive psychosocial outcomes were attributed by the authors to the participants' access to a multidisciplinary team of providers (Wagner, Muller-Godeffroy, von Sengbusch, Hager, & Thyen, 2005) . The sample size for this study was relatively small making the generalizability of the results questionable. The researchers may have overlooked other causes contributing to the results of their study since they limited their data collection to the German KINDL-R, which is a psychometric tool containing 24 items that yield six dimensions. No theoretical framework was readily identifiable as the foundation for this study. Based on the authors' discussion of the study one may conclude some sort of adaptation model may have formed the framework. This study reinforces the necessity for additional studies targeted at understanding the influences of positive outcomes in type-1 diabetes.

In a cross-sectional study of children eight to 17 years with type-1 diabetes, parental involvement was determined to have an impact on glycemic control (Anderson et al., 2002). The investigators concluded targeted interventions would be appropriate to provide optimal control to families with a type-1 diabetic child. The authors did raise a valid question at the conclusion of their study. The investigators were unable to determine whether or not conflict within the family rose because of concern over poor glycemic control or if poor glycemic control was a product of family conflict. These types of questions can easily be explored in a grounded theory study.

Summary of Quantitative Studies. Quantitative studies consistently demonstrate a clear understanding is lacking regarding how to maintain HgA1c below 8% by parents of children with type-1 diabetes. Interventional studies have found that some support in

the form of education and equipment may be useful to parents; however, the studies do not fully address the strategies these parents should use to maintain adequate glycemic control. In aggregate these studies indicate there is not much difference between interventions and some intervention no matter what it is results in a slight improvement in glycemic control. Survey results have been limited in scope by the framework used to develop them, possibly excluding meaningful elements from measurement. All of the studies reviewed offer strong evidence the generation of new knowledge is necessary to more accurately describe the care approaches used by families that are successful in optimal glycemic control.

Qualitative Studies. Qualitative studies, primarily phenomenological in nature, have evaluated the lived experience of participants. Some of these studies are focused on parents with a child with a medical condition regardless of the condition.

Focus groups and one on one interviews were used, as a data gathering technique in a study focusing on the specific psychosocial information needs of parents supporting children with health care needs (Jackson et al., 2008). This study identified four major themes for information intervention needs:

- Levels of support
- Delivery of information
- Relationship between the family and professional
- Management of events

While this study did build a case for the importance of providing information to parents when dealing with the health needs of their child, it was only one dimension of care approaches that were necessary for parents. What other dimensions are lacking?

A similar study focused on children with chronic diseases using social theory as a framework. In this study the goal was to provide evidence for tailoring interventions to the unique needs of the patient, providing support and acknowledgment patients do have a variety of unique needs that are not completely understood (Griffiths et al., 2010).

The literature does not fully identify what care approaches are useful to parents to manage their child's type-1 diabetes. Children are dependent on their parents for care, and more so when the child is affected by a chronic illness with the long-term health consequences that type-1 diabetes has, such as limb amputation, organ failure, and even death ("American Diabetes Association," 2012). In order to inform evidence based practice and to support effective policy it is necessary to understand and create meaning from parents who are faced with managing a type-1 diabetic child. Looking at those children who are well managed can provide useful insight in helping parents whose child is not as well controlled.

Conclusion

While clinicians use measures of HgA1c to quantify how well a child's type-1 diabetes is managed, relatively few parents hit these targets despite the long-term consequences of poor control. There may be barriers to good glycemic control that are still not well understood. To date, no research has provided the knowledge necessary to consistently and significantly improve glycemic control, nor has research defined an effective consistent evidence based guideline to support parents in their care of their child with type-1 diabetes.

Through in depth analysis using case study methodology insight may be provided on approaches that may be useful to parents caring for a child with type-1 diabetes. This

insight may provide the groundwork for future studies; provide valuable information for practice, and knowledge to inform meaningful health policy. Future research can continue to explore and measure effective interventions and support for parents of a child with type-1 diabetes. The rigor advocated by Yin's (2009) approach to case study methodology will inform this study using multiple cases to triangulate the explanation identified through thorough data analysis including an extensive audit trail (Yin, 2009).

Chapter III

Methods

Purpose

The purpose of this study is to deconstruct and reconstruct the phenomenon of parents successfully caring for a child who is a type-1 diabetic, using Parse's theoretical framework of human/becoming. This theory focuses on the human being's participative experience in the world (Parse, 1992). The end result of this process will be to explain how parents caring for a child with type-1 diabetes achieve good glycemic control.

Case Study Methodology

This study will explore the meaning a parent successfully caring for a child with type-1 diabetes ascribe to this phenomenon. Because this study gives voice to the parent involved in a complex situation Creswell (2009) recommends a qualitative method of study. The central question in the study is: "How does a parent successfully care for a school age child with type-1 diabetes?" Yin (2009) claims the case study methodology is effective at addressing research questions that are "how" questions.

Case study methodology is a research approach that evolved over time. The first generation of the methodology culminated in the Chicago School of Sociology in the early 1900s in which an anthropologist's field study was practiced on contemporary society in the surroundings of the University (Platt, 1992). The second generation of the case study also evolved out of grounded theory methodology as a result of the work done by Strauss, from the Chicago School of Sociology and Barney Glaser from the Columbia School of Economics (Glaser & Strauss, 1967).

Each of these men brought a slightly different lens to grounded theory methodology. As an economist Glaser brought more of an empirical lens to the methodology while Strauss's lens was more of a qualitative lens of the sociologist. While

these men would diverge in their philosophical underpinnings of the grounded theory methodology over time there was a consensus the methodology involved inductive reasoning.

Yin (2009) took the next step in the evolution of qualitative research moving it towards a naturalistic inquiry coupled with qualitative inquiry (Yin, 2009). This inquiry process uses all three principles of reasoning to conclude with a non-statistical generalization of the phenomenon of interest (Stake, 1995). The three principles of reasoning include deductive, inductive, and abductive.

Inductive reasoning utilizes specific data to offer theory generalization and conceptualization founded in the data. According to grounded theory generalizations arise out of the data (Glaser & Strauss, 1967). Since case study utilizes three forms of reasoning the results from this type of analytical reasoning are compared and contrasted throughout the research process.

Deductive reasoning is similar to a quantitative experiment in which the researcher starts with a testable hypothesis and the consequences are deduced from the findings. During this process it is possible to verify whether or not the theory is valid to the case under consideration. Yin (2009) compares this process to theory evaluation in a naturalistic environment (Yin, 2009).

Finally, abductive reasoning looks at unexpected facts, applies some rule, and posits the case may be true. It is a form of reasoning coined by Charles Sanders Peirce (Peirce, Christean, & Kloesel, 1992). Ginsburge (1989) identifies this type of reasoning as reconstruction of historical data from a few facts, also known as the “evidential paradigm” (Ginsburge, 1989).

Over the development of the case study methodology there has been some differing ideas about what a case study is (Gillham, 2000; Merriam, 1998; Miles & Huberman, 1994; Yin, 2009). All of these individuals agree a case is the object of a study and should be a complex functioning unit to be investigated in its natural context with multiple methods. Yin's (2009) case study methodology, which is the methodology that will be closely followed in this study, places the majority of his emphasis on the methods and techniques that constitute the case study. Rigor is achieved through in depth documentation and triangulation of techniques illuminating the phenomenon from varying angles and exploring numerous propositions (Yin, 2009).

The essence of a case study is triangulation between techniques, methods, strategies, or theories (Yin, 2009). Triangulation is commonly used in quantitative research to demonstrate the criteria of validity have been met and as a demonstration of rigor (Creswell, 2009). Triangulation in qualitative research is the process of validation comparing findings from one method with findings from another method (Holloway & Freshwater, 2007). As such, it will be important to incorporate all three methods of reasoning as the study progresses. Yin (2009) supports an approach that facilitates exploration of a phenomenon within its context through a variety of data sources. A constructivist approach claiming truth is relative and based on one's perspective is a major philosophical thread throughout Yin's work (2009). The advantage of using this approach is the close collaboration between the participant and research enabling the participant to have a voice in their view of reality (Searle, 1995).

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constructivist co creates data and analysis from shared experiences with participants and other data sources (Charmaz, 1990, 2000, 2006). Constructivism is informed by symbolic interaction in which meaning is created through interactions and actions ("Symbolic interaction in the twentieth century: The rise of empirical social theory," 1996). The advantage of using this approach is the close collaboration between the participant and research enabling the participant to have a voice in their view of reality (Searle, 1995).

The entire process will be documented providing evidence of rigor and an audit trail so additional studies can be developed from this study. This rigor will include the concepts of external validity, internal validity, construct validity and reliability. To demonstrate external validity Parse's (1992) theory of human /becoming was used not only in the single case analysis as the framework but also in replication logic in across the cases was compared. Internal validity in this study will be applied to exploratory inquiry demonstrating that certain conditions lead to others. Pattern matching will be an integral part of the internal validity of this study. Construct validity will be demonstrated through the use of multiple sources of evidence carefully documenting the chain of evidence. The key informants will have an opportunity to review the conclusions of the study. Reflexive development of the protocol will demonstrate reliability of the study (Yin, 2009).

One of the challenges of a case study is to define the case. It is important to have boundaries on a case (Yin, 2009). This case will be defined as a parent successfully caring for a child with type-1 diabetic as evidenced through good glycemic control in the context of patients seen at a local diabetic clinic for children.

Parse's theory of human/becoming

Parse's theory (1981) was originally known as man-living-health during a time when man referred to human kind (Parse, 1981). As the term evolved Parse altered the terminology used to describe her theory (Parse, 1992). Parse recognizes the human being as a whole and does not differentiate the various parts of body mind and spirit to make up that whole (Parse, 1992). Philosophically, the theory is comprised of three main principles, which include meaning, rhythmicity, and cotranscendence (Parse, 1981, 1987).

Principle one, meaning, is compatible with a constructivist approach used by Charmaz in which humans construct meaning from their way of being in the universe (Charmaz, 2006). Knowing evolves through the individual's own meaning and language is a tool used by the individual represents this meaning (Parse, 1995). This symbolic interaction was used to inform the constructivist approach to data analysis, and was used in this study (Charmaz, 2006).

Principle 2, rhythmicity, relates the co-existence of patterns when humans relate to each other. By selecting one side of a pattern the human has by definition moved from the other side of the pattern (Parse, 1995). Intentionality is a key component of rhythmicity and is evidenced throughout Parse's work (Parse, 1981, 1987, 1992). This study examined those parents who have rhythms that result in an optimal HgA1c rather than those who have made choices that have resulted in sub-optimal HgA1c.

Finally, principle 3, which specifies humans create new ways of viewing what is familiar to them will be addressed (Parse, 1995). This principle moves beyond the moment and addresses the pushing-resisting rhythm humans' experience (Parse, 1995). In this study those parents who have resolved the conflict created when a child has type-1

diabetes and developed new ways of creating a unique way of being that results in positive outcomes for their child was studied.

The overall goal in using this theoretical framework for this study is to understand how the parent successfully manages a child with type-1 diabetes as described by the person (Parse, 1981). This study views the person as having his or her own epistemology and ontology. The researcher respected this while conducting the study.

Study Parameters

Setting.

This study accessed participants through a local clinic affiliated with a children's hospital specializing in diabetic management of children. According to the medical director of endocrinology at this clinic, the clinic serves approximately 1200 families with diabetic children. About 30% of the families prefer Spanish. It is estimated that about 400 of the diabetic children are school age defined between the ages of six and 12 years of age. This study also used the clinic's definition of school age.

Interviews were conducted either in the clinic setting or another location that was more preferable to the participants. All participants were provided with a copy of the informed consent they signed after being given the opportunity to ask questions. All participants were provided with a copy of the informed consent for their records. A copy of the informed consent is provided in appendix C.

Since the rigor of case study analysis as advocated by Yin (2009) is improved by triangulating data, three cases were compared. In addition there was constant interaction with other research studies, reviewed to facilitate the analysis of the data and to help provide explanation to the data of this study.

Since this clinic only allows research to be conducted with a primary investigator who is employed by the clinic a Nurse Practitioner who sees diabetic children in the clinic agreed to act as the primary investigator. Internal Review Board approval was sought at the clinic prior to the University of San Diego IRB approval. Participant selection and recruitment commenced once both IRBs had approved the study.

Participant Selection.

Purposeful sampling was used to identify those participants that were able to provide information that was rich and relative (Stake, 1995). This type of selection allowed a non statistical generalization of the analysis based on the contribution each of the participants was able to make with their lived experiences.

Parents of a child with type-1 diabetes who was experiencing good glycemic control between the ages of 6 and 12 was considered for inclusion at the start of the study. This study used the ADA Guidelines for good glycemic control of HgA1c less than 8% ("American Diabetes Association," 2012), and parents were selected who have achieved a HgA1c of less than 8% on their most recent clinic visit with their child. Parents who prefer to speak English were recruited for inclusion in the study since the researcher was not fluent in any other language. The researcher felt that by using the services of an interpreter, nuances of verbal communication may have been lost in the translation process.

In order to maintain patient confidentiality the researcher did not have access to the patient records. The primary investigator at the facility identified possible participants and their phone numbers were provided to the researcher. A script is provided in appendix A for the initial call to the potential participant. The researcher also provided

the clinicians who were seeing patients who may qualify for participation with a letter that includes contact information for the researcher, appendix B. In addition, the research was available during several clinic days for a potential participant to meet with and schedule an interview time. This process also allowed the researcher to observe the clinic process providing additional data for triangulation. A meeting with the clinicians was conducted prior to the start of recruitment and observations from this meeting were documented to be used in the data analysis process.

During the meeting with the clinicians several concerns were raised that were addressed by the researcher. The first concern was the researcher uses the phrase “a child with type-1 diabetes” rather than the phrase “type-1 diabetic child”. The clinicians felt using the disease prior to the word child defined the child as the disease. This input is reflected in this study as well as the parent letter. Concern was also expressed over the thank you gift for the participants. Initially, the clinicians felt the majority of the participants would be upper socio-economic class and would be offended by a \$10 gift card. After some discussion it was determined that a Starbuck’s \$10 gift card offered with a simple thank you would be appropriate. The additional contribution made by the clinicians was the awareness of a possible bias in the study. There was a strong feeling some families with a child who had a HgA1c less than 8% may not reflect compliance. If these families chose to participate in the study they could skew the interpretation of the results. A HgA1c might reflect a more volatile blood sugar with significant highs and lows averaging into what appeared to be good glycemic control. The principal investigator at the facility did chart reviews to identify these families so the researcher could include the knowledge in the data analysis phase of this study.

Since this study used the case study methodology only three participants were recruited. Their data in the form of interviews was triangulated with each other, as well as with additional research, methods of analysis and observations.

Data Collection.

One-on-one interviews were conducted with the parent after informed consent was obtained. Appendix C. After review of the informed consent the researcher provided the parent with a copy of the signed consent form. Participants were assured they can drop out of the study at any time without retribution and that they can decline to respond to any question that may make them feel uncomfortable.

An interview guide was used for the interviews. Appendix D and E. This guide consisted of open ended questions designed to encourage the participant to comfortably share their experiences and feelings about their experiences. Demographics were collected prior to the start of the interview. A list of the demographics collected is provided in appendix E. All interviews were tape recorded and transcribed. The researcher did her own transcription immediately after the interview to allow an intimate understanding of the transcribed data.

Field notes were utilized as a tool to gather additional data. Impressions, thoughts, and ideas that occurred to the researcher while in the field were included in the field notes. Field notes are documentation of the experience in the field and reflect the rigor of the study by providing the documentation of the process (Emerson, Fretz, & Shaw, 1995).

Data Management and Analysis.

All data was de-identified and stored in a secure area. Field notes and memos were a part of the interaction with the data.

During the analysis phase of the case study, rigor increases through the use of a broad range of techniques that are not well articulated in the literature. Yin (2009) discusses an in depth strategy he outlines in his recent book. This strategy was followed for this case study analysis. As discussed in his book, it is important to have a roadmap of the technique to be used in advance of the start of the analytical process insuring the study addresses the original research question (Yin, 2009). As thoughts and hunches occur memos will be created providing the researcher with an intimate knowledge of the data prior to coding.

Data was manually coded following the three cycles of coding techniques discussed by Saldana (2009). These three cycles included selecting the appropriate coding, looking for patterns and theoretical coding, and then focusing the coding (Saldana, 2009). This process also allowed the researched to “play” with the data to further develop the analytical strategy (Yin, 2009). During the cross-case synthesis, word tables were created so the individual case data could be displayed using some uniform framework for each case (Yin, 2009).

Yin offers four possible analytical strategies. These include: Relying on theoretical propositions, developing a case description, using both qualitative and quantitative data, or examining rival explanations. Since this study has a theoretical orientation guiding the analysis the first strategy was used (Yin, 2009). Rival conceptual frameworks were examined to explain this phenomenon demanding that elements of the

fourth strategy are included. It is not uncommon for this fourth strategy to overlap the other three strategies and in fact may increase the validity of the findings (Yin, 2009). The researcher is aware of some of the rival frameworks and attempted to collect evidence about the possibility of “other” influence (Yin, 2009).

One of the key elements of a meaningful study is to incorporate not only multiple methods in data gathering techniques but to also use multiple analytical techniques. Yin identifies five key techniques. These include pattern matching, explanation building, time series analysis, logic models, and cross case synthesis (Yin, 2009).

Pattern matching was done on both the independent and the dependent variables of the study Yin & Moore (1998). The dependent variable was the child’s HgA1c value and the independent variables were the parental strategies of how they care for a child with type-1 diabetes. The pattern matching was conducted between the three cases interviewed and also between literature and theories.

Rival explanations were analyzed comparing patterns to the rival explanations. These patterns were used to refute or accept rival explanations. Successful matching provides evidence that a framework is an accurate framework (Yin, 2009). Frameworks were used from representatives of each of the four main categories of nursing midrange theorists. The researcher used categories identified by Meleis as needs theorists, interaction theorists, outcomes theorists, and caring/human theorists (Meleis, 2007). Parse (1981, 1987, 1992, 1995, 1997) developed the theoretical framework for this study and represents the caring/human theorists. Roy (1970) was used as a representative of the outcomes theorists. Orem (1995) was used as a representative for the needs theorists, and Peplou (1952) represented the interaction theorists.

Explanation building also overlaps the two previously discussed techniques. During this process the patterns were used to explain how parents achieve optimal glycemic control of their child. These explanations were then exposed to rival explanations to increase the internal validity of the study. The eventual explanation was the result of several iterations of explanation building as identified by Yin. These included:

- Making an initial theoretical statement of an initial proposition about policy or social behavior
- Comparing the findings of an initial case against such a statement or proposition
- Revising the statement or proposition
- Comparing other details of the case against the revision
- Comparing the revision to the facts of a second third, or more cases
- Repeating the process as many times as needed

(Yin, 2009).

Since this case is defined as a parent who is caring for a child with type-1 diabetes with good glycemic control, three cases were used for a cross case comparison. In addition, the literature was reviewed to compare to the analysis of the data.

The time series analysis technique was used to evaluate, through the participants voice, the trend for glycemic control over time. The researcher, during the interview process, asked the participant to discuss their care strategies prior to the diagnosis of their child, the initial diagnostic phase, the transition phase, and ongoing care strategies. During analysis the researcher looked at the trend of care strategies used by the participants. Since this analysis included multiple independent variables and one dependent variable, HgA1c, this analysis followed the guidelines of Yin's complex time

series analysis (Yin, 2009). The explanations was compared with outcomes as measured by HgA1c with the independent variables identified throughout the study, which included interactions within the family, and between the family and complex social structures, and between the parents and the child.

Logic models, the fourth strategy, overlapped the time series analysis as it addressed a complex chain of events of an extended period of time (Yin, 2009). Since this technique looks at causal events the researcher looked at episodes during the time series analysis from the reverse perspective of the independent variable becoming the independent variable (Peterson & Bickman, 1992). Elevated HgA1c at some point in the time series analysis may become the independent variable affecting responses to the child and responses to the HgA1c may be viewed as dependent. Through this process rival explanations can be entertained (Yin, 2009).

Finally, cross case synthesis, was considered. The literature was combed for additional case studies in this area. Since the initial literature review identified a gap in understanding of how parents care for a child with type-1 diabetes, this particular technique was a challenge. In order to facilitate a robust analysis other research methodologies focused on a specific aspect of the anticipated complex strategies identified other research methodologies were considered for this studies analysis phase.

All of the above forms of analysis overlap and offer stronger support of the results that came from this study.

Strengths and Limitations of Method. An initial limitation of this study is the researcher's limited experience using case study methodology and diabetes care. This limitation also provides a strength in that the researcher came to the study without

expectations of the outcome except those that may be formed by her own bias as a single middle aged woman with a well managed chronic disease.

Participants were included based on their child's HgA1c. HgA1c reflects glycemic control over a three-month period ("American Diabetes Association," 2012). A child who has had multiple extreme fluctuations in blood sugars throughout the three months prior to the HgA1c results may still reflect a HgA1c that is 8 or less and the parents may not be using a care approach that provides optimal management of the disease. It is also a possibility that these parents chose not to participate in the study. The clinicians at the study site conducted chart reviews to identify families who may fall into this category so that this information could be used during the analysis phase. None of the three families did fall into this category.

Since this study is limited to participants who speak English as a primary language, culture variations may be missed. The results of this study will need further exploration with participants of other cultures even though three cultures were represented but the three parents.

Qualitative research studies may not be visible in practice (Sandelowski, 2004; Sandelowski, Docherty, & Emden, 1997) identified four main reasons that qualitative research was not visible in 1997, and these reasons still apply today. They are:

1. In practice the use of research is defined as measurable outcomes. Models of research utilization focus on applying findings from quasi-experimental studies focusing on the technical aspects of patient care.
2. Many clinicians have an inadequate understanding of qualitative research.

3. Qualitative researchers tend to resist accumulation and synthesis of their studies.
4. The misunderstanding that their results need to be subjected to testing hampers qualitative researchers.

(Sandelowski et al., 1997)

One additional reason why qualitative research may not be as visible in the clinical setting is the lack of documentation when a clinician applies something learned from reading a study. This decrease in visibility is slowly changing and qualitative studies are beginning to emerge to build the science. An example is Wuest's partnership with a quantitative researcher to further develop her grounded theory of *precarious ordering* into a measurement tool (Wuest et al., 2006) for use in quantitative research (Wuest et al, 2006).

Conclusion

Explaining how parents caring for a child with type-1 diabetes using case study methodology will provide the necessary information for a foundation to fill a large gap in the literature. Understanding this phenomenon in the population proposed by this study will inform future studies within this population and similar populations. Ultimately, support for evidence-based practice, and new knowledge for health policy will be available as a result of the initiation of a program of research through this study.

Chapter IV

Results

Introduction

The overall purpose of this explanatory, case study research was to explore how parents successfully care for their school age child with type-1 diabetes. Applying Parse's theoretical framework for nursing research the three major themes of the theory informed the researcher. These were meaning, rhythmicity, and cotranscendence (Parse, 1981).

Consistent with this theory a constructivist approach was used in analyzing the data using the premise of symbolic interaction (Charmaz, 2006). The specific aims of the study were as follows:

1. To understand how parents know through their own value principles to care for their child with type-1 diabetes;
2. To explore how parents co-create a rhythmical pattern with the universe that results in good outcomes for their child with type-1 diabetes;
3. To describe how parents create new ways of viewing the familiar;
4. To explore how parents create new means of caring for a child with type-1 diabetes through interconnectedness with other people.

Sample

This case study compared three cases to validate the analysis through triangulation. Parents of children between the ages of 6 and 12 were considered for this study. They were recruited at a local children's' endocrinology clinic in Southern California. Ultimately, three parents from different families agreed to participate. The clinic serves approximately 1200 families with children who have diabetes. This estimate of the number of families with children who have diabetes was provided by the medical director and includes all types of diabetes. Approximately 400 of the diabetic children are

school age. Thirty percent of the families are documented as preferring Spanish, leaving seventy percent who speak English or another language other than Spanish. Sample characteristics are displayed in table 1.

Family ID And Marital Status	Ethnic Background	Number Of Children	Age of Child With Diabetes	Add'l Chronic Diseases of Child with Diabetes
C1 Married to child's father	Vietnamese Immigrant	1	12	Asthma
C2 Married to child's father	Mexican Immigrant	3	12	0
C3 Married to child's father	Caucasian	3	12	0

Table 1: Sample characteristics

The three cases in this study used for cross case comparison provided information through the lens of three different ethnic groups. All of the cases were homogenous in age. The size of the family was consistent across two of the ethnic groups and all of the cases were married to the father of the child with type-1 diabetes, and it was their first marriage.

Data Analysis

Data included the transcripts from an approximately one-hour interview of each of the parents representing the cases. Interviews were tape recorded and immediately transcribed after the interview by the researcher. The transcriptions were manually coded using Saldana's (2009)(Saldana, 2009) three cycle coding methodology. Field notes, memos, and observations were documented and a literature review was conducted

concurrently to data analysis. All of these approaches were incorporated into this research to demonstrate validity and reliability.

Interview analysis. All three of the cases provided consistent data demonstrating many commonalities between each of the cases in spite of their cultural differences. The differences were in the words used to describe a similar concept. For example, C1 expressed the fear she felt in causing pain to her child by pricking her with a needle as “cold in her heart”. C2 described her fear as “scaring me”, and C3 described the fear as “it hurts me even though he doesn’t complain”.

These interviews were analyzed with the overarching research question in mind broken out by the aims. All of the three cases had demonstrated a close knit family unit that ultimately perceived the child with diabetes encouraged their family to live a healthier lifestyle.

Pre Diagnosis phase. Each of the participants had known something was not right with their child prior to the child’s diagnostic event. This phenomenon addresses aim one of the study, or parents’ ways of knowing. In C1 both parents and multiple relatives experienced type-2 diabetes and were familiar with the symptoms. C2 had a friend whose child had type-1 diabetes and they had discussed it on multiple occasions. C3 had a father-in law who had passed away because he was a non-compliant type-2 diabetic. In each case, life’s experiences had influenced not only how the parent knew something was wrong with the child but also helped with the transition from the diagnostic episode to parental home care of the child.

Interestingly, each of the parents had been ignored by the health care system when they attempted to communicate something was wrong with their child. C2 had noticed

prior to a trip to Mexico her daughter had begun to drink “a lot a lot a lot a lot of water”. She shared her daughter was always tired and she had begun to lose weight. When the family arrived in Mexico, C2 took her daughter to the doctor who told her, her daughter was fine. When the family came back from Mexico, C2 had started doing research on the Internet. She made another appointment for her daughter as she felt strongly she was deteriorating. This doctor, “said I shouldn’t worry, I kept saying no you have to test her”. Finally, after being sent home on several occasions they were sent to a local hospital for testing. At the end of the testing they were sent home from the hospital. The next day C2 was alarmed by her daughter’s condition and drove her to her doctor. The doctor was surprised to see them as the doctor had thought the daughter had been immediately admitted to the hospital. C2 shared by the time her daughter was admitted her blood sugar was 700.

C3 had a similar experience to C2. Her son was actively participating in gymnastics. Her son had hit his head one day during gymnastics. This was a Saturday. She said he felt fine afterwards so did not take him to the hospital until Monday when he started to complain of pain on the left side of his neck. When they arrived, the providers told the mother her son was fine. She responded knowing something was wrong with her son “they didn’t want to do a CT Scan that he required and finally when I yelled at them they did it and told me he was a perfectly healthy boy”. This young man continued to deteriorate through the week and went from 114 to 101 pounds. By Wednesday he began complaining of a stomachache. C3 indicated that she and her husband thought he had the stomach flu. By Friday the son had started to throw up. C3 said “I knew there was something really wrong with him”. C3 took her son back to the hospital and finally

convinced them to check his blood. He was then rushed to the local children's hospital, and the mother was told, had she waited any longer he would have died. C3 became teary eyed when she expressed the guilt she felt at encouraging her son to eat and drink. She said "I was killing my son".

C1 had a slightly different experience in the diagnostic phase. Since C1 and her husband suffered from type-2 diabetes, the daughter had witnessed her parents checking their blood sugar. One day the daughter did not "feel well" and asked to use her mother's blood glucose strip. The daughter was then taken to the hospital. C1 stated, "She said she just feel it coming". Then the mother admitted "No uh It wasn't well I seen that it was coming".

Family Routine Pre Diagnosis. Each of the cases analyzed had connected active lives prior to the diagnosis of their child. C3 was actively involved in the Moorman Church, and her husband was a Bishop in the church. The extended family was very strong. She shared, "my husband's family is very very tight knit, I mean we see each other three times a week, we go together to church, there are 13 kids and they are more like siblings than cousins so it affected all of them, so when they knew they all wanted to do something for him". C3 gave birth to her son several days before her brother in-law had a son. Both boys are very close and the families participate together in multiple social activities.

C1 has only one child. Since C1 has no other children she describes her relationship with her child, "I told her I would be her mother sister friend, I think being close to a parent helps her through it because I am right next to her, not far away like I am her actual friend". C1 had a traditional family structure prior to the diagnosis of the

child, which seemed to carry through after the family stabilized from the diagnostic phase. C1 described her family life as “normal”, she and her husband take a pill for their diabetes. “Yes my husband too and my mom and my sister brother all diabetes it’s genetic in my family you know”.

C2 had brought her husband to the interview and both were engaged in the interview, but only the mother responded to questions with the exception of the father crying at certain points in the interview. This family was very involved with their extended family. Regular visits were made to Mexico, Las Vegas and the Central Valley of California to spend time with family, this also carried over once the family life stabilized after the diagnostic phase.

Diagnosis Phase . Each of the participants had their diagnosis phase culminate in a three-day hospital stay for their child. C2 described the relief she felt once her child was hospitalized.” She was fine because she was safe in the hospital.” The mother laughed during the interview and seemed to relive the relief she felt once her child was being taken care of. She shared while laughing, “she started crying because she was afraid they were gonna take out all of her blood”. At the end of this both the husband and wife look at each other and smile. “So I would laugh and tell her she wasn’t going to run out of it!”

The only information C3 shared related to the hospital phase was the fear that she felt and the anger and frustration at being ignored prior to the hospitalization. She shared “...because one of the nurses told me, had you waited one more day we just have to make him comfortable and let him go and that’s like my heart just dropped to the floor he barely make it, he barely make it.” When C3 was sharing this story she was visibly angry.

C1 expressed primarily fear at the hospitalization phase. She said, “I got scared you know, then she went in the hospital and she stayed three days, then I don’t know what to do”.

In none of the interviews was the provider encounter a significant part of the information shared. All three participants did indicate some type of discharge education was done, but none of them seemed to feel comfortable in their knowledge of what to do for their child after discharge, nor did they choose to share what they were taught prior to discharge when they were asked. When questioned about the discharge process all three of the cases acknowledged the question and moved on to what they did to learn how to care for their child when they got the child home.

Post discharge phase. All three of the cases confessed fear of their child being readmitted to the hospital motivated them to actively seek knowledge to keep them out of the hospital. These parents also used this fear with their child to get them to follow the parent’s instructions on what the child should do.

C1 said, “You don’t want her in the hospital again you know?” Even when questioned about support from the health care system after discharge, the mother answered with what she and her daughter did to manage her diabetes. This mother talked a lot about the food pyramid and how the food pyramid is balanced with her daughter’s activity level so she has enough energy to get through her basketball each day. The most difficult adaptation the mother had to make on discharge was to give her daughter her insulin shots. “I gonna crying every morning, every morning I am crying and I am crying taking her to school and I come back and I pray to God please give her a way diabetes I don’t wanna shot her every morning.”. During this portion of the interview the mother

cried and at the end of exploring the transition home from the hospital she said that giving her daughter a shot was the hardest. Never did C1 address questions about provider support with the exception of saying that in between appointments at the endocrinology clinic if the daughter has an issue they seek help with the allergist for her asthma even if it is not an asthma related problem.

All of the family was active in seeking knowledge when C2's daughter was discharged. It was shared the providers did come in to provide discharge teaching but C2 said, "When we took her home we did not know what to do". She continued describing the experience by saying, "I was like I prayed to God to give me like something so I can give her something and then my other daughter would be good to look things on internet so I asked her to look at like what are carbohydrates and like what is protein and what are portions and so her sister would help me." Initially, C2's daughter was very dependent on the mother for what foods she could eat and when there was disagreement fear of re hospitalization was used to gain compliance. The diagnosis of the child caused the family to be healthier. "Our routine changed. We ate very specific times and we all ate together." "It not only helped her but it helped my whole family because of her we are all more healthy".

The C3 interview response was very similar to the response received by C2. When asked about provider involvement in the transition to the family life after the hospital stay. When asked about assistance, the participant responded with her understanding of healthful eating and the family had already engaged in healthful eating prior to the diagnosis of her son. She indicated she made a few changes in the family's diet by switching to brown rice. She said her husband is pleased because this diagnosis

has encouraged her to be more healthful. Some of the challenges the family faced upon discharge was watching her son get his finger pricks and insulin shots. She said, “Just seeing him pinch his fingers draw the blood it is kind of hurtful”. She went on to explain about his siblings and cousins, “They know it it is painful even though he doesn’t even flinch”. This mother also utilized fear of pre hospitalization to get her son to do something he didn’t want to.

Letting go. All three of the cases have moved toward allowing their child more freedom. It was very obvious watching the non-verbal communication this was an extremely stressful and emotional process for the families. Consistently across the cases the participants talked about their fears along with the realization they would not always be with their child. This realization that they would not be with their child at all times has led each of the cases to involve with increasing degree to participate in decision making.

C1 included began to include her child early on in the decision making process. She said, “My daughter and I decided we didn’t want to do that anymore so we decided to manage the diabetes so we could get control of her life back.” She went on to say that the pump has made it easier recently to manage her diabetes, but her daughter decided to go back to shots since the pump interfered with her basketball game. Her daughter decided on her own to do her own shots so she didn’t have to see her mother cry. Her mother included her in the shopping trips and the daughter has become very good at reading the labels on the food.

In slight contrast to C1, C2 had a little more difficulty letting go. Upon discharge CHOC provided the mother with some books to help her understand diabetes. The mother would read these books and then transfer the information to her daughter to prepare her

for independence. “I would tell her she needed to get to know her own body. I would read the books and tell her when you are low you feel shaky or dizzy your sugar might be low and she wasn’t sure and she would say “yeah mom”. I would tell her I will not be with you every second of every day.” As the parents began to let go C2 expressed the worry that they felt. She said, “We would worry we had trouble telling her yes and we didn’t know if she would do the right thing because her blood sugar would go really low and she would faint and her friends wouldn’t know what to do”. During the discussion of the daughter’s independence transition the father cried quietly. The C2 said she and her husband would tell her daughter “if you want to live a good life you have to do it.”

When C3 discussed this process with her family C3 was very proud of her son’s motivation to manage his diabetes and visibly sat up and lifted her head while talking about it. She indicated the biggest motivation for her son to become independent and manage his diabetes is his long-term goal of becoming an Olympic Gymnast. C3 attributes her son’s ability to be independent to the teaching at home she and her husband provide their children. She is confident and demonstrates this by saying, “I just teach him what is right, what is wrong, and everything else is himself and he wants to do it or not it is himself.”

Summary. All three of the cases demonstrated similar intentional choices in each of the rhythms they were experiencing. Table 2 is a word table that was used in the analysis of the data comparing the words used to describe each of the choices made in each of the paradoxes identified.

Phase/Paradox	Case 1	Case 2	Case 3
Pre Diagnosis: Assertive/passive	<p>"...and accidentally figured it out."</p> <p>"I got scared you know"</p>	<p>"I kept saying no you have to test her"</p> <p>"They sent us home without telling us anything."</p>	<p>"...and finally when I yelled at them they did it..."</p> <p>"...they didn't do anything else but xrays. Okay, then I took him home."</p>
Hospitalization: Active participation/ disbelief & shock	<p>"My daughter and I decided to manage the diabetes."</p> <p>"Then she went in the hospital and she stayed three days then I don't know what to do."</p>	<p>"We had to learn how to take care of her before we could take her home"</p> <p>"...and then we were shocked.."</p>	<p>"I ask for the physician to come see him I don't care if he don't want to get up."</p> <p>"I was just like out of my like in a haze."</p>
Discharge: Knowledge/ ignorance	<p>"...food always think about food."</p> <p>"I don't know something she explain to me, I don't understand she take me through it step by step." (when talking about her doctor) ."</p>	<p>"My other daughter would be good to look things on the internet so I asked her to look..."</p> <p>"When we took her home we didn't know what to give her."</p>	<p>"..They did want to get the Fruit Loops but no more of that."</p> <p>"So almost loose one of our children not that we love him any more than any of our others it is just the fear."</p>
Autonomy: Letting go/Control	<p>"I don't worry too much because she takes care of her own diabetes."</p> <p>"I think being close to a parent helps her through it because I am right there next to her not far away."</p>	<p>"She would do her homework and go out to play with the neighbors I worried but she told me she would be okay."</p> <p>"I would tell her you are eating this and she wouldn't want to always but I told her you are eating this."</p>	<p>"I just teach him what is right what is wrong everything else is himself."</p> <p>"Yeah because when I tell him that he gets a cold just check your ketones and he just says oh mommy I just don't want to do it I wanna go back in the hospital?"</p> <p>Nononononono he goes and checks it."</p>

Table 2: Word Table

Demographic data. All of the cases involved children who have been well controlled as evidenced by their HgA1c. All of them have had a HgA1c less than 8 since discharge from the initial hospitalization. In addition none of the cases involved children who had experienced any readmissions to the hospital since the initial hospitalization. C1's daughter was diagnosed at ten years of age and was 12 at the time of the interview. C2's daughter was nine when she was initially diagnosed and is now twelve. C3's son was ten at diagnosis and is now 12.

Observations. Observations were documented from several sources. These included clinic observations, a staff meeting observation, and observations during the interview process.

Clinic. The endocrinology clinic where all three of these cases are seen on a quarterly bases are bustling. Upon arrival the families must stand behind a line to check in. Check in is computerized using touch screen, but there is a person behind the counter to help those families who have difficulties checking in. There are stacks of brochures recruiting for clinical trials in multiple locations around the waiting room. Appointments seem to occur on a very tight schedule with a medical assistant inviting the family back to an exam room. Entrance to the examination area is controlled by a security system that is activated by a clinic employee who scans an employee badge to open the door. Since the clinic is situated next to the children's hospital other pediatric clinics are occurring throughout the building.

Staff meeting. The Medical Director of the endocrinology clinic requested the researcher attend a clinicians' meeting to discuss the details of the research study. The researcher was invited into the clinicians' staff meeting about 20 minutes later than the

scheduled time. A PowerPoint presentation had been requested with an overview of the proposed study. The researcher prepared handouts with information on qualitative research. Many of the clinicians had difficulty grasping the concept of qualitative research and a lengthy discussion occurred regarding the value and need for qualitative research. Recruitment was to be partially the responsibility of the clinicians so additional time was spent on the recruitment process and the protection of the family's privacy.

Prior to this meeting the researcher had met with the nursing department's research committee at the request of the medical director of the endocrinology department. There was a significant amount of irritation communicated to the researcher at the clinicians' staff meeting because they were not aware of the study prior to the nursing department. This was handled by explaining the process that the researcher had gone through to get this far in the research process. The researcher was also challenged on the thank you gift and several other items in the proposal some of which were addressed in the proposal. At the conclusion of the meeting the clinicians agreed to participate in the recruitment of participants.

During the staff meeting one of the physicians was paged to talk to a family who was out of town and whose child was recently diagnosed with diabetes. There seemed to be a general annoyance in the room with the interruption and several of the providers present made sarcastic comments after the call was completed referencing the family as "needy".

Multiple levels of providers were present at the meeting. Overall, there were about 20 present and included in the 20 were physicians, nurse practitioners and nursing

staff. One physician expressed particular interest in qualitative research and asked for references to read further on it. These were provided.

Literature review. As the researcher immersed herself into the analysis of the study the literature was consulted as concepts and themes began to evolve. Results from many of the studies supported the knowledge that was developed throughout the analysis phase even though the study population was slightly different than those included in this study.

A group at the University of Alabama evaluated the autonomy of the adolescent with type-1 diabetes (Dashiff, Vance, Abdullatif, & Wallander, 2009). In this study the adolescent was defined as between the ages of 11 and 15 years. This age range overlapped the age range of the individuals looked at in this study. The study conducted at the University of Alabama used attachment theory to inform the research and evaluated both the child and the mother. The purpose of the study was to determine whether or not attachment processes inhibited cognitive autonomy and if cognitive autonomy was related to self-care behaviors in the adolescent. The study did find cognitive autonomy was directly related to self-care and maternal anxiety did affect cognitive autonomy. Factors that were measured other than separation anxiety did not demonstrate an affect on cognitive ability of the adolescent (Dashiff et al., 2009). This study was longitudinal and supports the findings of this study by demonstrating mothers who address their separation anxiety have better outcomes of encouraging self-care for their child after one year. The study did not look at the impact of cognitive autonomy on the outcome of disease management, but did support the importance of interconnectedness described in Parse's theoretical framework (Parse. 1995). .

Another mixed methods study looking at the family environment of diabetic adolescents also supported the results of Dashiff et al (2009) (Dashiff et al., 2009) study and the data obtained from this study. Structured interviews and surveys were conducted independently with 58 adolescents and mothers. Good glycemic control was associated with decreased anxiety, an increased self concept, increased cohesion within the family, decreased conflict within the family. and encouragement for the adolescent to behave independently (Anderson, Miller, Auslander, & Santiago, 1981).

A randomized interventional study accessing 749 randomly selected participants at a single urban medical center, looked at the impact of discharge on readmissions and emergency room utilization within thirty days of discharge. The intervention included assigning a nurse discharge advocate while the patient was hospitalized, to work with the patient and family to prepare the patient for discharge. Two to three days after discharge a clinical pharmacist followed up to review medications and impress on the patient the need to follow the discharge plan. The providers and participants were not blinded as to who was in the interventional group and who was not. The study found there was a significant decrease in the number of patients accessing the hospital or emergency room within the thirty-day time frame (Jack et al., 2009). While this study did not focus on children it did bring to light the importance of helping the patient with the transition home from the hospital.

An earlier qualitative study, also used a survey, to analyze the parents' perception of their needs after their children with diabetes had been discharged from their initial hospital stay. One hundred sixty four parents were surveyed and 20 were interviewed. The need for support after discharge was a strong statistically significant theme in the

study's data (Smith & Daughtrey, 2000). All three of the cases in this study struggled to get information after their child was discharged from the hospital.

As the research began to identify the phases that each of the cases experienced in the data, the literature was consulted. A phenomenological study of parents experience with a diabetic child less than three was reviewed. This study found the parents went through three phases that the researchers identified as the diagnosis and hospitalization phase, the adjusting to care at home phase, and the long-term adaptation phase (Hatton, Canam, Thome, & Hughes, 1995). Since this study focused on very young children, the parents were not yet faced with preparing their child for independence.

A document published by Diabetes Care was created by a task force including representation from the American Association of Diabetes Educators and the American Diabetes Association, which was created in the summer of 2006. The focus of the task force was diabetes self-management education (DSME). This document published in January of 2009 stresses the necessity of diabetes education so patient outcomes can be improved. The document was based on evidence from multiple studies on diabetes education and standards were created based on this review. The standards do not appear to have been applied to the participants in this study. The standards are as follows:

1. The DSME entity will have documentation of its organizational structure, mission statement, and goals and will recognize and support quality DSME as an integral component of diabetes care.
2. The DSME entity shall appoint an advisory group to promote quality. This group shall include representatives from the health professions, people with diabetes, the community, and other stakeholders.

3. The DSME entity will determine the diabetes educational needs of the target population(s) and identify resources necessary to meet these needs.
4. A coordinator will be designated to oversee the planning, implementation, and evaluation of diabetes self-management education. The coordinator will have academic or experiential preparation in chronic disease care and education and in program management.
5. DSME will be provided by one or more instructors. The instructors will have recent educational and experiential preparation in education and diabetes management or will be a certified diabetes educator. The instructor(s) will obtain regular continuing education in the field of diabetes management and education. At least one of the instructors will be a registered nurse, dietician, or pharmacist. A mechanism must be in place to ensure that the participant's needs are met if those needs are outside the instructors' scope of practice and experience.
6. A written curriculum reflecting current evidence and practice guidelines, with criteria for evaluating outcomes, will serve as the framework for the DSME entity. Assessed needs of the individual with pre-diabetes and diabetes will determine which of the content areas listed below are to be provided.
7. An individual assessment and education plan will be developed collaboratively by the participant and instructor(s) to direct the selection of appropriate educational interventions and self-management support

strategies. This assessment and education plan and the intervention and outcomes will be documented in the education record.

8. A personalized follow-up plan for ongoing self-management support will be developed collaboratively by the participant and instructor(s). The patient's outcomes and goals are the plan for ongoing self-management support will be communicated to the referring provider.
9. The DSME entity will measure attainment of patient-defined goals and patient outcomes at regular intervals using appropriate measurement techniques to evaluate the effectiveness of the educational interventions.
10. The DSME entity will measure the effectiveness of the education process and determine opportunities for improvement using a written continuous quality improvement plan that describes and documents a systematic review of the entities' process and outcome data.

The guidelines provided by DSME appear to meet the discharge needs of the patient and their family, but do not appear to have been implemented for the families in this case analysis. All three cases did express the value support would have meant to them upon discharge. C2 stated she would appreciate ongoing opportunities for support and education.

Interview observations. All three of the case interviews were anxious to share their experiences. Many of the experiences appeared to elicit strong emotions regardless of the length of time that had passed since the participant had experienced them. C3 appeared very angry at being ignored when she had attempted to communicate her “mother’s way of knowing”. This was evidenced by a more erect and rigid body language

during the discussion of this topic, as well as a narrowing of the eyes and lips. All three participants were saddened by the change in processes the child would have to go through to manage their newly diagnosed chronic illness. This was expressed with tears. C2 and C3 became furtive when talking about letting go so their child could develop some independence from them. C1 expressed as strong of an emotion but was more resigned that her daughter knew what she was doing and she had to trust in that fact. The strongest emotions were in evidence during the pre diagnostic phase, the discharge home and re stabilizing family life phase, and the letting go phase. What was not said the strongest was the lack of involvement of the health care providers tasked with helping the parents manage the disease process.

Chapter V

Discussion

Introduction

Research findings using greater than two case studies provides a more robust analysis than a study using two or less (Yin, 2009). Each of the three cases analyzed for this study are relevatory and unique. The overall purpose of this study was to explore how parents' achieve good glycemic control for their school age child with type-1 diabetes. The study addressed four how questions: (1) parents know through their own value principles, (2) parents co creates a rhythmical pattern with the universe, (3) parents create new ways of viewing the familiar, and (4) parents create new means of caring through interconnectedness with other people.

Chapter 5 reviews the data collected using Parse's theoretical framework (Parse, 1992). The internal validity will look at the pattern matching. Pattern matching for rival explanations will also be done to improve the internal validity. External validity will be demonstrated by defining how the studies' findings can be generalizable (Yin, 2009). Construct validity, which has been described in depth in the methodology section, will be summarized. Reliability, or the demonstration the study can be recreated with the same results will be demonstrated. Finally, the significance to nursing, recommendations, study limitations, and conclusions will be discussed.

Parents' ways of knowing

As C3 shared "mothers' know". The information across C2 and C3 provided by the mother was consistent with the work of Belenky, et al (1997). Both of these mothers felt frustration and anger at not being heard. C2 and C3 knew something was terribly wrong with their child prior to diagnosis, but when they attempted to communicate with

their doctors they were told their child was fine. In both cases the absence of acknowledgement of the mother's concerns resulted in an emergency situation and ultimately hospitalization of the child. In a constructivist world talking requires careful listening (Charmaz, 2006). C1 and C2 had their voice rendered silent while they were desperately seeking help for their young child.

C1 presented her child to the doctor with empirical evidence. She had at her disposal blood glucose strips she and her husband used to manage their type-2 diabetes. When her daughter used one of these strips she could present facts to the doctor. This empirical evidence was taken much more seriously than the evidence C2 and C3 attempted to communicate with their doctors.

During the hospitalization phase all three of the cases expressed a feeling of safety and relief their child was being cared for. Even though all three cases indicated they received education during this phase, the information did not seem to have a significant influence fulfilling the needs of the mother's taking care of their child after discharge. All three women were not able to assimilate the procedural knowledge they were provided while their child was hospitalized into a meaningful routine after discharge.

After the discharge of their child each of the women interviewed embarked on a quest for knowledge necessary to successfully care for their child. This quest was done with varying degrees. C1 had a working knowledge from first hand experience with her own type-2 diabetes. Her biggest challenge was learning to poke her daughter to give her shots and monitor her blood sugar. Eventually the daughter took over to minimize the emotional pain her mother was feeling from inflicting pain on her daughter. Both C1 and

her daughter learned how to manage the food pyramid by frequenting the grocery store and reading labels. C2 and C3 did reading on the subject of diabetes management. Her daughter's sibling in this process assisted C2. This learning process all three of the women went through was communicated as if it were a natural process. Lyons (1983) feels a mother's feeling of responsibility leads to "natural" learning (Lyons, 1983).

As the family settled into a new routine the child with type-1 diabetes in each case began to seek increasing amounts of independence from their parents. Each of these parents listened to what their child was saying to them, and while it was difficult to begin the process of letting go of the control they had imposed after the child was discharged from the hospital. Belenky (1997) describes the increase in knowledge that women gain through listening to others as a core characteristic of how women know. What women do with this knowledge then defines the rhythms that the child with diabetes and the parent settle into.

Rhythmical Patterns

The rhythms these families experienced throughout the process of caring for their child with type-1 diabetes are similar in nature to the rhythms of the human heart. During a steady regular rhythm the heart is healthy and efficiently sending the lifeblood out to the body. When an arrhythmia occurs the heart is expending a significant amount of energy in a random fashion and is ineffective at sustaining the body for long. Eventually, the asynchronicity can lead to collapse of the system. Figure 1 demonstrates the various phases each case experienced through the process of caring for their child with type-1 diabetes.

Parse describes the rhythmical way in which humans exist as a paradox (Parse, 1992). Each phase the parent experienced with their child provided a differing paradoxical way of being. As demonstrated in figure 1, the pre diagnosis phase each case struggled with assertiveness/passivity. C1 was not as challenged to make a choice in these responses since she had empirical data to present to the providers. C2 and C3 were more challenged as their voice was not heard and as a result had to become increasingly more assertive to be heard. During the hospital phase all three cases reacted similarly to the hospitalization phase of their child. They operated in the paradox of disbelief and shock/ active participation. Since the participants operated more on the shock side of the paradox they were unable to receive the information provided to them by those caring for their child in the hospital.

Upon discharge C1, C2, and C3 all transitioned into the paradox of knowledge seeking/ignorance. None of the cases chose to operate on the ignorance side of the paradox. All sought knowledge in their own way. Interestingly, none of the three women sought additional help from health care providers. C2 did value the written information provided to her by the facility. All three cases felt a variety of classes after discharge would have been helpful as they struggled with how to care of their child with type-1 diabetes.

As each case learned to live with and care for a child with type-1 diabetes the child began to challenge the parent for increasing amounts of autonomy. This autonomy was in the form of social activities and pursuing athletic goals. The paradox the parent was challenged with was letting go/maintaining control. Each of the parents interviewed acknowledged that they were not going to always be around for their child. They began

teaching the child how to recognize when they were getting into trouble and how to respond.

A pervasive theme throughout all of the phases after discharge was the fear of the child being readmitted to the hospital. Each of the cases had used that fear early on to encourage the child to cooperate with the management of the diabetes. There was also a loud absence of involvement with the health care provider for support and information.

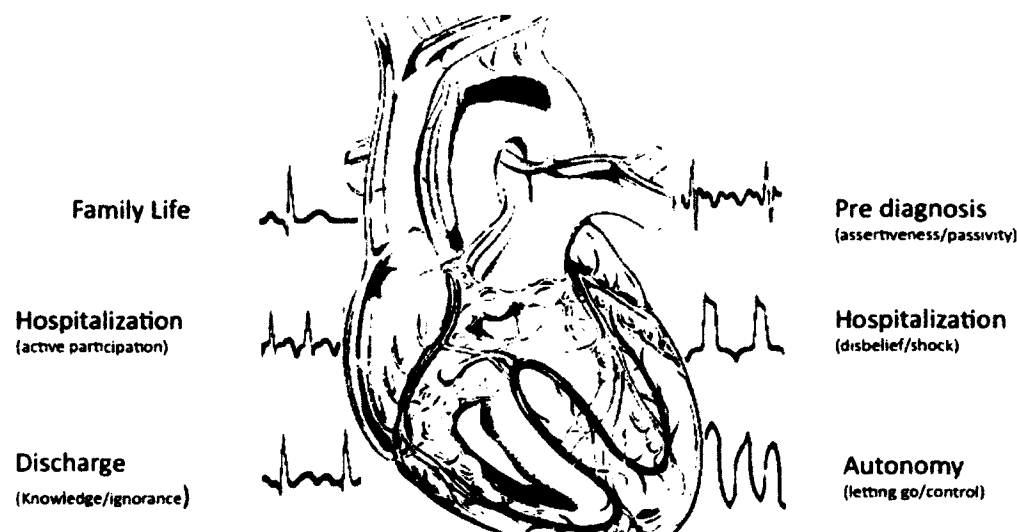


Figure 1: Rhythmical Patterns

New ways of viewing the familiar

The epistemic and ontological evolution of the parent in caring for their child with type-1 diabetes was consistent throughout the three cases. All three of the cases viewed the child with type-1 diabetes as a relationship that encouraged the rest of the family to live a healthier lifestyle. The parent co-created meaning, primarily, within the family structure. Interactions with the provider community occurred only on a quarterly basis to

assess labs and status of the patient. When C1's daughter experienced an illness that was not directly diabetes related an outside physician was consulted. Information through written form and through other social relationships was valued. C2 reported she obtained information prior to the diagnosis of her child through a friend who had a child with type-1 diabetes.

New means through interconnectedness

As the child moved through the process of pre diagnosis to seeking independence the interconnectedness the family experienced changed. The experience of learning their child had type-1 diabetes transformed the family. The focus of family life moved from the stable rhythms to revolving around the hospital. As they learned of the type-1 diabetes the family began to view food as an important part of family life. All three cases began structuring family life around meals. They became more cognizant of the food pyramid and all three cases spent time talking about it. Portion control was another theme that became pervasive in each of the cases. Concern about the child's social network was focused on the child's friend knowing what to do in case the child with diabetes "passed out". Using the universe as a visual the figures following this discussion demonstrate the change in the interconnectedness. Figure 2 demonstrates interconnectedness of the family structure prior to the diagnosis of their child. It is much like the universe in which the family is the core with other structures revolving around it. During the hospital phase figure 3 demonstrates how the interconnectedness changed to include the hospital as one universe connected to the universe of the family. After diagnosis, Figure 4 demonstrates how the new knowledge their child has type-1 diabetes alters some of the relationships that were evident prior to the diagnosis. The family continues to be the core of the

universe but the hospital is always looming out there and something to fear. Figure 5 shows how the child begins to co-create as its own universe separate from the original family universe although there is still a tight connection between the two. Of note in figure 4 and 5, is the movement of the health care system out of prominence in the relationships.

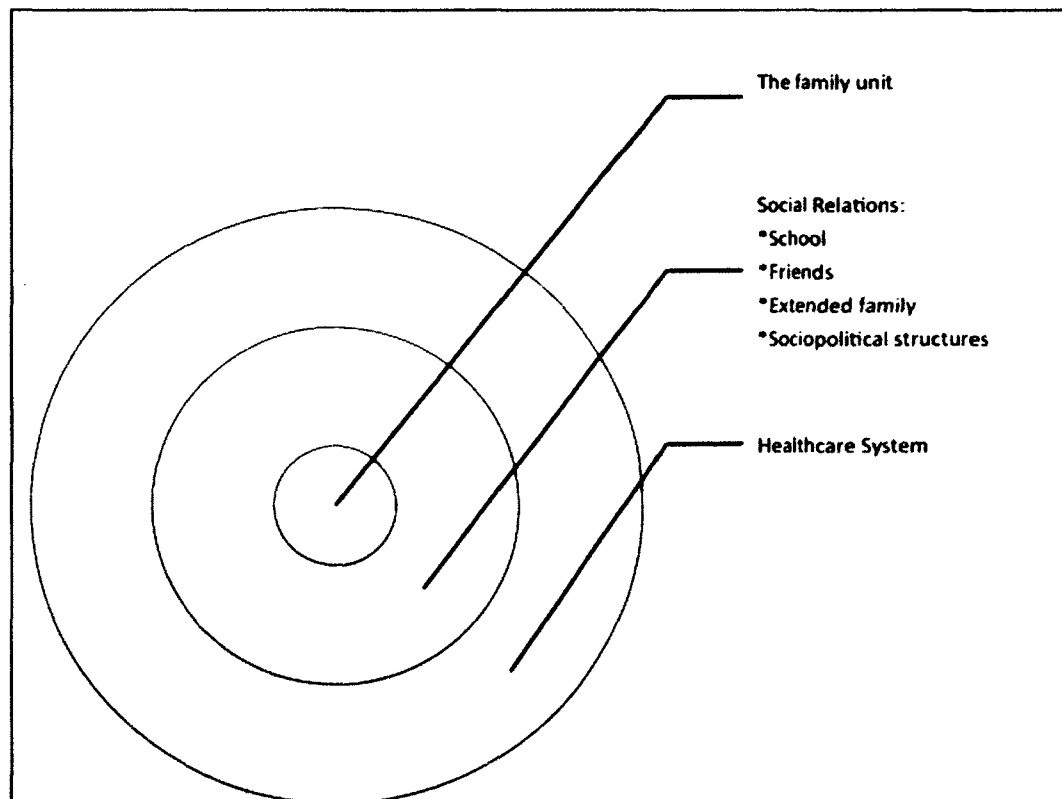


Figure 2: Family Interconnectedness Pre Diagnosis

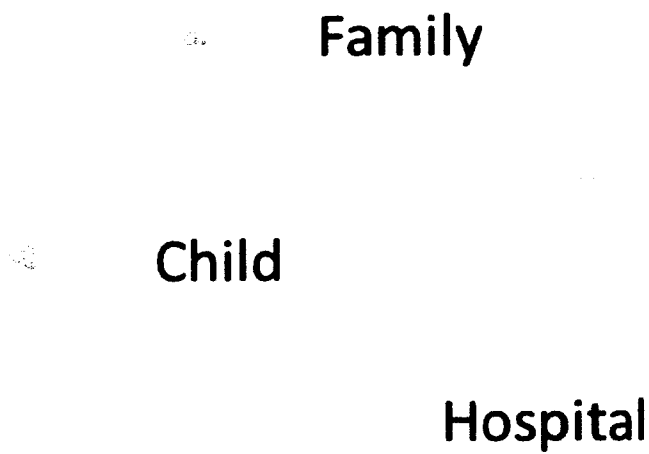


Figure 3: Family Interconnectedness During the Diagnosis Phase

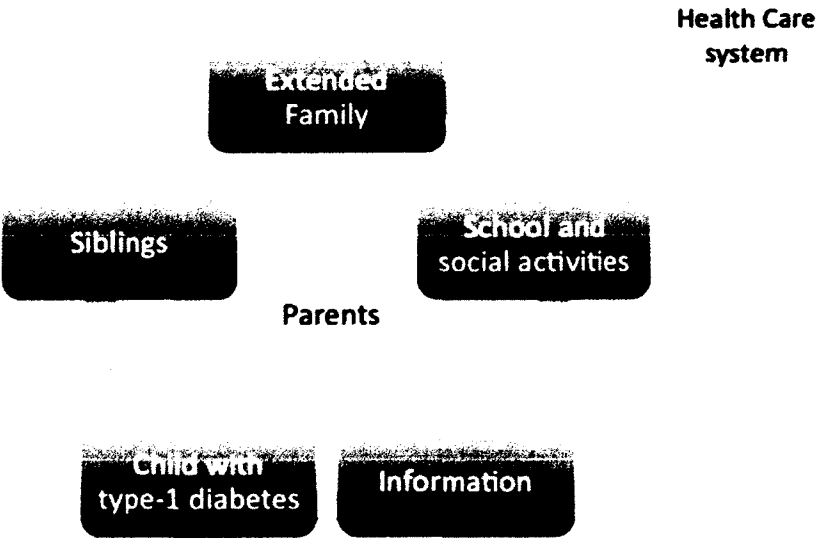


Figure 4: Interconnectedness Post Hospitalization

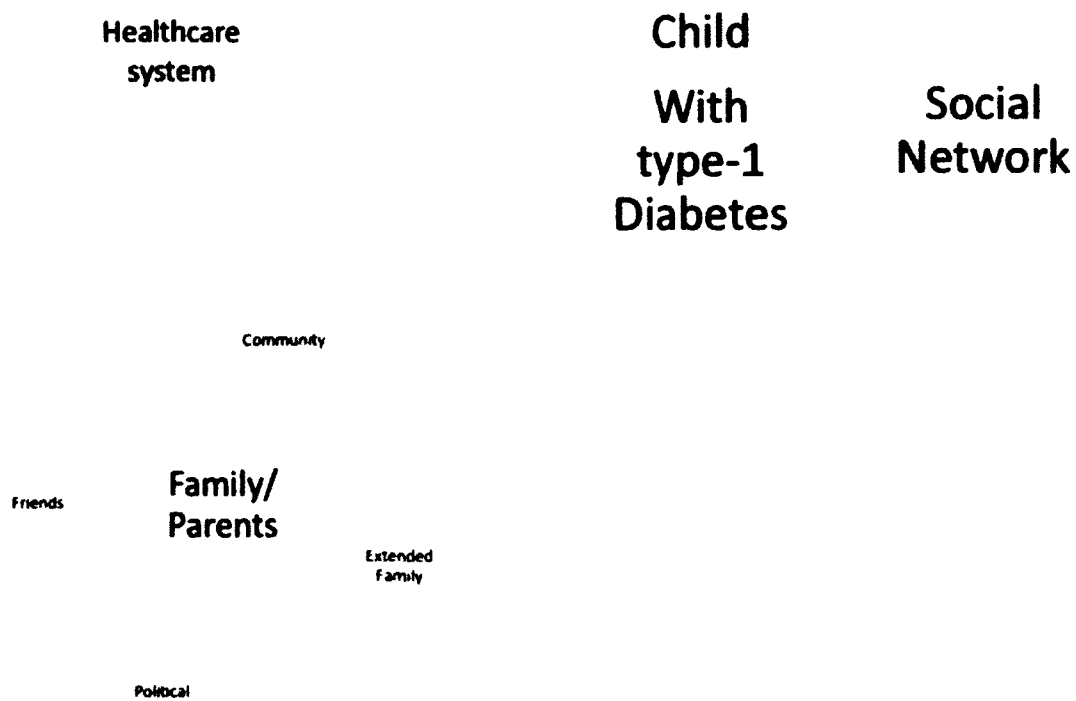


Figure 5: Co creation of the Child's Own Universe

Rival Theories

Parse's theory of Human-Becoming provides a good framework for what is happening in families who are experiencing good outcomes for their child with type-1 diabetes (Parse, 1997). To increase the internal validity of this multiple case study analysis, rival theories will be evaluated to demonstrate other theoretical frameworks do not adequately explain how parents successfully care for a child with type-1 diabetes (Yin, 2009). A representative of each of the four categories in nursing midrange theory has been included for evaluation.

Roy's adaptation theory. Roy (1970) began building a theory of how humans adapt to their environment that focuses on health and illness as a continuum and the theory is very outcome driven. She continued to develop her theory over time focusing on how a nurse acts on the individual or family to affect change (Roy & Andrews, 1999). Her theory minimizes the importance of the intentionality of the individual and family's response to their way of being in the universe, which evolved as a key theme in the analysis of this study.

This study did use an outcome measure to select participants for this study. The purpose was not to focus on the measurement itself and what nurses could do to achieve that outcome, but to explain how parents through intentionality are able to achieve these outcomes. The results of the study demonstrate parents co create meaning in spite of nursing interventions. Roy's model shows the nurse as an active participant in the patient's ability to adapt to an illness. The parents in these case studies did not focus on the illness but on the maintenance of a healthy family unit. Future research may identify ways nursing can help parents' co create meaning when they are not achieving the desired outcomes. Roy's theory may be appropriate to apply in a health care setting but falls short for families who are not actively engaged with the health care system.

Had Roy's theory been the framework of this study a significant body of data would have been minimized and the researcher would have focused on the provider interactions with the participants and their families. The subject of provider interaction and intervention was a very limited portion of the information communicated to the researcher. In each case the researcher had to prompt the participant to discuss his/her provider interactions and in each case, very little if any response was given to these

questions. The majority of strategies evolved from the participant's worldview and ways of being.

Peplou. Peplou's theory is based on the nurse patient interaction leading to a goal-oriented result (Peplou, 1952). The nurse following Peplou's theoretical framework would respond to the problem at hand (Peplou, 1952).

Problem solving skills in this theory do take into account the interpersonal relationship, but the theory is limited in supporting a parent who is developing a long term strategy for successfully caring for a child with type-1 diabetes within the context of the family and the universe. These strategies, as communicated by each case were not task oriented as described in Peplou's work (1952). Strategies the parent had developed were founded in their interactions and interconnectedness with their world. These parents were not helpless in their situations, but developed intentional choices in their day-to-day life that resulted in the outcomes they were experiencing with their child that had type-1 diabetes.

Orem. Orem's self-care theory acknowledges the need for the individual or family to take action to sustain life. The nurse operating under Orem's theory would eliminate the knowledge deficit of the individual or family.

This theory ignores the timing of the individual's needs and is a temporary response. Orem talks about the transition of the care from the nurse to the individual or family, but is limited to the present interactions with the nurse. The perception of what the individual or family needs is up to the nurse, and the patient voice is silenced through the process (Orem, 1995).

Summary. The researcher has divided the nursing theorists into four main categories and chosen one representative from each category. Each theorist within a main category has similar strengths and weaknesses in their theory to others within the same category. Table 3 summarizes the comparison of rival theories. The categories are; Needs theorists, interaction theorists, outcomes theorists, and caring/human theorists (Meleis, 2007). Parse falls into the category of caring/human theorists, and was used for the framework of this study.

Theorist	Category/Theory	Strength	Weakness
Parse	Caring Human/Becoming	Humans viewed as a whole 3 Principles: 1-Rhythm 2-Meaning 3-co transcendence	Nurse needs to understand and listen to the individual/family voice
Roy	Outcomes Adaptation	Is focused on the outcomes	Minimization of intentionality and individual/family response focus is on illness
Peplou	Interaction Interpersonal Relations	Focus on interactions	Task oriented. The nurse focuses on the problem at hand
Orem	Needs Self-care deficit	Need for family to take action	Family's voice in what is needed when is silent

Table 3: Comparison of theorists

Validity

Construct. Yin (2009) recommends that to demonstrate construct validity two areas must be addressed. The first is to define the concept and to relate it to the objectives of the study. The second is to identify operational measures matching them to other publications.

The concept of good glycemic control for children with type-1 diabetes has been standardized and regularly evaluated by the ADA ("American Diabetes Association," 2012). It is defined as a HgA1c of 8 or below ("American Diabetes Association," 2012). This is the measure used to select cases for this study. Each one of these cases had a recent HgA1c at 8 or below. For the purpose of this study school age was defined as children ages 6 to 12 years of age. Parents who care for a well-controlled school age child with type-1 diabetes have learned strategies to successfully care for their child. The overall objective of this study was to explain how these parents achieve good glycemic control for their child with type-1 diabetes.

Internal. A threat to internal validity occurs when the researcher incorrectly concludes one set of actions or circumstances led to another (Yin, 2009). The researcher followed a theoretical framework throughout the study. Furthermore, rival explanations were considered. Pattern matching was one method used in this study to increase the internal validity of this study. The explanation built in each of the three cases analyzed were compared and contrasted. A time series analysis followed the complex patterns communicated by the parents that made up the strategies they used to care for their child (Yin, 2009). The time series started with pre diagnosis and analyzed the data through the phase of letting go. Overlaying the time series analysis Yin's fourth strategy for data

analysis was incorporated into the data analysis phase of this study. Logic models look at a complex chain of events over time to identify casual events. Similar explanations were found in each of the three cases. All of these methods used in this study have increased the internal validity of the study (Yin, 2009).

External. The results of this study were generalized to Parse's theory of human becoming. Yin's (2009) replication logic was used to demonstrate the findings of the case study could be generalized outside of the study. Generalizability, although a term associated with quantitative research is also used in some qualitative research (Yin, 2009; Glaser and Strauss, 1967). Three cases were purposely selected for the contribution that each could make to the analysis.

Reliability

Reliability in case study research is based on another researcher's ability to replicate the same results using the same case (Yin, 2009). Careful attention was paid to the description of the methods used in this multiple case study analysis. All documentation of the procedures used have been included

Significance to nursing

Nursing practice. The goal in Parse's (1992) practice methodology for nursing is the quality as described by the person and family, with sensitivity to respecting the worldview of others. The philosophical underpinning for nurses is the view of the person as the coauthor of health (Parse, 1992). The results of this study support the need to allow voice to the individual and family for nursing. All three cases experienced the same phases of learning to care for their child. In each of the phases the parent had different needs. By integrating this awareness into nursing practice, families who are less capable

of achieving good glycemic control independently may be offered the appropriate support at the appropriate point in time.

Education. This study demonstrates two key areas for nursing education. The first area is the importance and awareness of the theoretical framework nurses integrate into their practice. By integrating a theoretical framework that is inappropriate, the needs of the patient may not be met. As evidenced by the cases in this, study health providers may not listen to their patients. Since the nursing profession is developed around caring and an integral part of caring is to provide advocacy for the patient, the concept of hearing what the patient is trying to say is an important one to incorporate into practice curriculum. This study also provides information to educate nursing specific to families with a child that has type-1 diabetes. What nurses may think is an appropriate intervention may be ineffective if provided at a point in time the individual or family is not receptive to it, therefore rendering it ineffective.

Shared decision making is a concept that has been gaining momentum in the health care provider community. It is a collaborative process between the patient and the physician incorporating evidence based practice. It requires the health care provider to have an understanding of what is important to the patient incorporating a knowledge of the patient's lifestyle. (Informedmedicaldecisions.org, 2012). This concept was lacking for the families who participated in the cases for this study. More focus on this process during the education of nurses may improve the patient experience.

Research. This study demonstrates the need for additional research focused on the epistemological and ontological place families find themselves with their child. The interventional studies discussed in the review of the literature may not have realized the

level of significance that was first expected because the phase the family was in was not considered. Perhaps an interventional study educating families after the discharge of the patient from the hospital would find more value than a study evaluating the effectiveness of education for the family while the patient is still in house. Sensitivity to the individual and family's current interconnectedness could inform future research in this area.

Additional qualitative studies replicating and expanding the inclusion criteria can be conducted to strengthen the results of this study and expand on them. Including those parents who are struggling to achieve good glycemic control can be compared to those achieving poor glycemic control. Studies of parents caring for children with other chronic conditions may also benefit from the knowledge gained from the cases in this study.

Health Policy. Using strategies and tools that are useful to patients has been missing from some recent health policy ending in unexpected or disappointing outcomes. Much of the research currently in use to develop health policy is founded in economics. Economics measures the motivations and behaviors of consumers as influenced by financial factors. Health care is much more complex and can not be reduced to simple supply and demand factors. This study offers a glimpse into the needs of the patient and parent. Informing health policy through the voice of the patient and parent may provide a more realistic insight into how the policy will affect them.

Recommendations

Many qualitative studies are not visible in the clinical environment(Sandelowski, 2004). Evidence-based practice is an approach to health care that builds on the clinician's knowledge through the integration and assimilation of research (Melnik, Fineout-Overholt, Gallagher-Ford, & Stillwell, 2011). Current evidence supporting advances in

clinical practice for children with type-1 diabetes has alleviated some suffering and pain while providing some improvement in health outcomes. As evidence-based practice continues to evolve, all forms of rigorous methodology is necessary to improve the transformation of research into practice, including qualitative research.

This study can contribute to the understanding of strategies that support good outcomes for the parents of children with type-1 diabetes. By listening to the individual and family members, nurses can offer the appropriate intervention at the time that is most meaningful to the recipient, improving the effectiveness of the intervention.

Study strengths and limitations

The overarching limitation of this study is the researcher's inexperience in qualitative research and more specifically in case study methodology. As a result of this limitation, it also allowed the researcher to be in the moment with the participant to listen carefully to what was said and not said by the participant. By not having any preconceived ideas about what the responses should be, the researcher allowed the participant to coauthor the results of this study.

An additional limitation of the study was the limited access the researcher had to the participants' medical records. The limited access was a stipulation of the facility in allowing an "outsider" to recruit at their facility. If the researcher had access to the medical records additional quantitative data could have been gathered to add to the triangulation of the data during the analysis process.

As pointed out by the clinicians at the facility, using HgA1c as the only inclusion criteria could have brought bias to the study. HgA1c is an average of glycemic control over time and as such it could represent periods of poor control. Since none of the cases

included a child with type-1 diabetes who had been re hospitalized or had suffered from complications of their diabetes the researcher concluded the HgA1c was a good representation of good glycemic control. The principle investigator at the facility verified this conclusion for the researcher by conducting a chart review.

The three cases that were compared covered three different ethnicities increasing the generalizability of the analysis across multiple ethnic groups (Yin, 2009). In comparing across ethnic groups there may have been nuances and or biases by the researcher based on her frame of reference, that included being a middle aged single white woman with a chronic disease.

Conclusions

School age children with type-1 diabetes receive the majority of care from their parents. When the parents do not have effective strategies for caring for their child, the child throughout life suffers significant consequences. Providing meaningful support to families improves outcomes for their child, in other words provides the child with the opportunity to lead a long healthy life. Explaining how parents successfully care for their child with type-1 diabetes can affect future research, practice, education, and health policy.

This study has identified areas that require a closer look to improve outcomes for all children with type-1 diabetes. First and foremost parents have a unique relationship with their child and their voice needs to be heard. Targeting interventions at times when the parent and child are receptive to hearing the information and assimilating it is very important. Supporting parents when they are teaching their child to become independent

may affect the child's health and ability to care for their type-1 diabetes for the rest of their life. Improving outcomes now for children will have lasting effects in their future.

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APPENDIX A

When the phone call is answered:

Hello, my name is Elizabeth Ciaccio and I am a nursing PhD candidate at the University of San Diego. Are you the parent of " fill in name of child"? If not may I speak to a parent?

Once the appropriate person is engaged on the phone:

I am conducting a study to identify effective strategies that parents use when caring for their child with type I diabetes. This study is being conducted through the clinic at CHOC/Mission. You have been identified by your provider at the clinic as achieving good glycemic control with your child. I would like to respectfully request your participation in the study. Participation would mean an interview lasting approximately one hour with me at a time and location that is convenient for you. There may be follow up questions after the interview. I would like to assure you that your decision to participate or not in no way affects the care of your child through the clinic and you can drop out of the study at any time without consequences. Do you think you may be interested in contributing your strategies to this study?

If the response is yes:

Are you prepared at this time to schedule a time and location or would you like me to call back once you have had an opportunity to review your calendar? If the individual does want a call back I will ask for a convenient time. I will thank them for their willingness to participate and leave them with my contact information.

If the response is ambivalent:

I am happy to provide you with additional information if you are unsure, or to call back once you have had an opportunity to think about the study and discuss your participation with your family. If the individual would like a call back I will request a convenient time. I will thank the individual for their willingness to consider participation and leave them with my contact information.

If the response is negative:

At anytime during the conversation if the individual expresses feelings that they have no interest in participation. I will thank them for their time leave them with my phone number in case they change their mind and discontinue the phone call. If the individual indicates that the timing of the phone call is inconvenient for them then I will ask if there is a better time for me to call them.

Notes:

If the individual has questions during the call I will provide responses consistent with the IRB proposal. At no time will the individual be pressured. Consent for the study will be done in person as described on the original IRB application. If the individual would like verification that I am authorized to conduct this study through the clinic I will refer the individual to the principle investigator.

APPENDIX B

Dear Parent,

I am a PhD student at the Hahn School of Nursing, University of San Diego and am working with Nancy Varni NP. Nancy Varni is a Nurse Practitioner in the CHOC Endocrinology Clinic. Ms Varni will be the Principal Investigator on the research that I am conducting to complete my PhD. My dissertation will evaluate what parents with children that have type-1 diabetes are doing to care for their child so that they remain in good health. You have been identified by your provider as having good outcomes with the care of your child. I hope to explore with you the approaches that are useful to you so that other parents may benefit by applying your approaches to the care of their child who has type-1 diabetes.

Participation in the study is completely voluntary and participants can withdraw at any time without consequences. Participation will include a one-hour interview discussing the care approaches that are useful to you. After the initial interview there may be a follow up to clarify the meaning of your comments in the initial interview or to explore comments you made in the initial interview further. All interviews will be kept in strict confidence and any reference to them in writing will de-identify your personal information.

If you think you would be interested in participating or if you have further questions about the study you can contact me at 714-743-4870, or email me at lizciaccio@yahoo.com. Nancy Varni, NP can be contacted at 714-532-8895 or via email at nvarni@choc.org. I hope to hear from you. Thank you for your consideration.

Sincerely,

Elizabeth Ciaccio, RN, PhDc

APPENDIX C

Children's Hospital of Orange County
 INSTITUTIONAL REVIEW BOARD
INFORMED CONSENT AGREEMENT

Grounded Theory Study of Parents Caring for a Child with Type-1 Diabetes

You are being asked to participate in a research study. Before you give your consent to volunteer, it is important that you read the following information and ask as many questions as necessary to be sure that you understand what you will be asked to do. If you don't understand something in this consent form, please be sure to ask your researcher to explain.

Investigators and Sponsor

Principal Investigator:	<i>Nancy Varni, NP</i>
Co-Investigator (s) :	<i>Elizabeth Ciaccio, RN</i>
Sponsor:	<i>University of San Diego, Hahn School of Nursing</i>

Purpose of this Study

The purpose of this study is explore the strategies that you use to care for your child with Type-1 Diabetes.

Why this is a Research Study

This is a research study because strategies that are useful to parents caring for a child with Type-1 Diabetes is not well understood.

Participants in the study are selected based on the age of their child that has Type-1 Diabetes and their child's recent hemoglobin A1c test. This study will focus on children between the ages of six and twelve that have a hemoglobin A1c at 8% or less.

Number of Participants to be Enrolled and How Long You Will be in the Study

Number of Participants: *Up to 25 participants will be included in this study at CHOC and study wide.*

You will be involved in this study for: *an approximately one hour face to face interview with possible follow up via phone email or face to face to clarify responses to questions during the initial interview.*

Procedures to be Followed During the Study

This is what will happen if you participate in this study:

Enrollment Procedures:

- *Your child's provider will identify you as a possible candidate for inclusion in this study.*
- *You will be provided with a "Dear Parent" Letter which offers basic information about the study and contact information for further questions*
- *The researcher may also be available during certain clinic times to further discuss the study with you and answer any questions you may have.*
- *Once you have decided to participate in the study the researcher will make an appointment with you to review this consent form and to conduct the initial one-hour interview. The research will make every effort to accommodate your schedule and provide you with options for a convenient location for the interview.*

Interview Procedures:

- *With your permission the interview between you and the researcher will be tape-recorded. All documentation including tape recordings will be coded to protect your confidentiality and will be maintained under lock and key for security purposes.*
- *The researcher will ask you several open-ended questions asking you to describe your experiences related to your child with Type-1 Diabetes. If at any time you feel uncomfortable responding you may convey this discomfort to the researcher and the interview can either terminate or can move on to the next question. The interview should take no more than 60 minutes.*
- *If you choose to terminate the interview prior to the conclusion of the questions you may do so with out any consequences to yourself or your child.*
- *Once the interview is concluded the researcher will transcribe your interview. If the researcher is unclear about a particular response that you made or identifies an area that clarification of what you were saying during the interview, the researcher may contact you to more completely understand your responses.*
- *After the interview has been transcribed, evaluated and possibly clarified with you no further efforts will be necessary on your part.*

You will be informed of any significant new information regarding the study or of any changes in the procedures as described.

Risks and Discomforts to This Study

There may be a risk that some of the information that you share during the interview is uncomfortable for you and cause you some emotional stress. Sometimes when people are asked to think about their feelings, they feel sad or anxious. If you would like to talk to someone about your feelings at any time, you can call toll-free, 24 hours a day:

San Diego Mental Health Hotline at 1-800-479-3339

These are the risks that we know about. There may be risks to being in this study that we don't know about now. You will be told of any changes in the way the study will be done and any additional identified risks to which your child may be exposed.

Benefits of the Study

While there may be no direct benefit to you from participating in this study, the indirect benefit of participating will be knowing that you helped researchers better understand how parents care for the child with type-1 diabetes.

Removal From This Study

You are free to withdraw your consent and discontinue your participation in the study at any time.

Questions About the Study

If you have any questions about the study at any time you can contact any of the following individuals:

1) Elizabeth Ciacchio

Email: lizciaccio@yahoo.com

Phone: 714-743-4870

2) Nancy Varni

Email: nvarni@choc.org

Phone: 714-532-8895

3) Mary-Rose Mueller, PHD – Dissertation Chairman

Email: mmueller@sandiego.edu

Phone: 619-260-4562

Confidentiality

Information gathered from you while participating in this study will be kept confidential according to applicable laws and regulations by the researcher and his/her staff, except that:

- The Sponsor of the study University of San Diego, Hahn School of Nursing and their representatives will receive information concerning the study .
- Certain agencies, either Federal or State may require information concerning this study.
- Certain legal actions may require disclosure

By signing the informed consent, you authorize such access to you data. If the results of this study are published, your identity will be kept confidential.

Cost/Compensation

If you participate in the study, the researcher will offer you either a \$10 Starbucks gift card or a Target gift card at the time of the interview.

You will receive this compensation even if you decide not to complete the entire interview session.

The law requires that CHOC submit an IRS 1099 form for individuals to whom it provides compensation exceeding \$600 per calendar year. Compensation provided by this research study will count toward the annual total for this purpose.

Participant Rights and Study Withdrawal

You are agreeing to be in this research study by your own choice. You can decide not to be in the study at all or you can decide to stop being in the study even after the study has started. No matter what you decide your child will still get your doctor's care and won't lose any other benefits you have now. You also won't be giving up any of your child's legal rights by signing this consent form.

It is important that you understand the details about this study. If you have any questions that haven't been answered, please be sure to ask your researcher or research coordinator.

If you have any questions about your rights as a participant in a research study, please contact the CHOC Institutional Review Board for the protection of research participants through:

Office of Research Compliance
(714) 532-8869

This research project has been reviewed by an institutional review board for the protection of the rights of human participants in research projects, in accordance with federal regulations. **This informed consent is not valid without the CHOC Institutional Review Board stamp of approval.**



Children's Hospital of Orange County
INSTITUTIONAL REVIEW BOARD
Human Research Participant's Bill of Rights
(For Medical Experiments)

Pursuant to the California Protection of Human Subjects in Medical Experimentation Act, any person who is asked to consent to become a participant in a research study involving a medical experiment or any person who is asked to consent on behalf of another has the right to:

1. Be informed of the nature and purpose of the experiment.
2. Be given an explanation of the procedure to be followed in the medical experiment and any drug or devices to be utilized.
3. Be given a description of any attendant discomforts and risks reasonably to be expected from the experiment.
4. Be given an explanation of any benefits to the participant reasonably to be expected from the experiment, if applicable.
5. Be given a disclosure of any appropriate alternative procedures, drugs, or devices that might be advantageous to the participant, and their relative risks and benefits.
6. Be informed of the avenues of medical treatment, if any, available to the participant after the experiment if complications should arise.
7. Be given an opportunity to ask any questions concerning the experiment or the procedure involved.
8. Be instructed that consent to participate in the medical experiment may be withdrawn at any time and the participant may discontinue participation in the medical experiment without prejudice.
9. Be given a copy of any signed and dated written consent form used in relation to the experiment.
10. Be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence on the participant's decision.

Signature and Consent

I have read the above information about the study, ***Grounded Theory Study of Parents Caring for a Child with Type-1 Diabetes***. I have had a chance to ask questions to help me understand what will be expected of me in this study. I agree to be in the study and I have been told that I can change my mind later if I want to. I have been told that by signing this consent form I am not giving up any of my legal rights. I have been informed that I will be given a signed and dated copy of this agreement which includes the Participant's Bill of Rights for my records.

_____ Name of Participant (printed)		_____ Age
_____ Signature of Parent/Legal Guardian or Participant if 18 Years of Age or Older		_____ Date
_____ Printed Name of Parent/Legal Guardian if Participant is under 18 Years of Age		_____ Relationship
_____ Signature of Witness	_____ Printed Name	_____ Date
_____ Signature of Person Obtaining Consent (Principal or Co- Investigator)	_____ Printed Name	_____ Date
_____ Signature of Translator (if used)	_____ Printed Name	_____ Date

APPENDIX D

Interview Guide

Demographics

- 1. Describe your experience caring for your child with type-1 diabetes.**
 - a. Describe you first memory of learning your child had diabetes.**
 - b. Describe your challenges**
 - c. Describe what makes it easy.**
- 2. Describe a typical day with your child.**
 - a. School**
 - b. Sports**
 - c. Diet**
 - d. Social**
- 3. Describe your interactions with your health care providers.**
 - a. How do you decide when to interact with your health provider**
 - b. Describe your ideal positive (negative) experience.**

APPENDIX E

Demographics:

- What other chronic conditions, if any, does your child suffer from?
- What is your child's age?
- What is your educational level?
- What is your child's gender?
- What is the participant's gender?
- How long has your child been diagnosed with type 1 diabetes?
- How often has your child been seen on an urgent or emergent basis? Did it end in hospitalization?

APPENDIX F

INSTITUTIONAL REVIEW BOARD APPROVAL

UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

Case Study of Parents Caring for a Child Having Type-1 Diabetes With Optimal HgA1c

by

Elizabeth Ciaccio

**A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
UNIVERSITY OF SAN DIEGO**

**In partial fulfillment of the
Requirements for the degree
DOCTOR OF PHILOSOPHY IN NURSING**

July 17, 2012

Dissertation Committee

**Jane M. Georges, PhD, RN, Chairperson
Cynthia D. Connelly, PhD, RN, FAAN
Linda D. Urden, DNSc, RN, CNS, NE-BC, FAAN**

ABSTRACT

Type I diabetes in school age children is a complex condition requiring continuous physical, nutritional, and therapeutic monitoring to prevent lifelong complications and maintain quality of life. In 2011, one in 400 children in the United States were affected by it. The purpose of this research study was to understand how parents achieve optimal HgA1c for their school age children with type-1 diabetes. Currently, there is very little research documenting how parents achieve this goal. Understanding this phenomenon more clearly can be used to inform future research, improve practice and provide information for development of effective health policy.

Management of diabetes in school-age children is a challenge for parents because of the requirement for variable insulin regimes, and is complicated further by the child's ever-changing needs due to growth and development and inability to identify potentially harmful hypoglycemic episodes. Yin's case study methodology was utilized in this study with Parse's human/becoming theoretical framework as an analytic basis. Careful attention throughout the study was paid to demonstrating rigor. Data were triangulated using rival midrange theories, cross case comparison, observations and literature. The three cases used for the cross case comparison represented three distinct ethnic groups. The human/becoming theory most closely supported the outcome of the data analysis offering evidence of rhythmicity, co-transcendence and intentionality. Each case analyzed consistently communicated similar experiences in the various phases of pre-diagnosis, hospitalization and diagnosis, discharge, stabilization and preparing the child for independence.

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